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Practice-Based Approach to Assessing and Treating Non-Adherence in Pediatric Regimens

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Abstract

With advances in medical care, youth with chronic illness have the potential for higher quality of life; however, these treatments often come with cost (i.e., burden, financial) that can result in non-adherence. Pediatric non-adherence, on average, is approximately 50% across chronic health conditions. Research has identified effective, evidence-based assessment measures and intervention strategies to promote regimen adherence in youth. Yet, these measures and strategies typically are designed for clinical trials and thus may not be feasible or practical in typical clinic settings. As the field of adherence assessment and intervention expands, it will be important to devise evidence-based tools that are pragmatic and can be translated easily into practice. To guide this future direction, the goals of this paper are to review evidence-based adherence assessment and intervention strategies that can be used with youth and families in clinical practice, to illustrate the complexities of addressing adherence concerns in routine practice, and to discuss the challenges of disseminating and implementing evidence-based strategies in the real world.

With the advent of increasingly effective medical treatments, many of which are delivered on an outpatient basis, children with chronic illness are able to achieve better health outcomes and a higher quality of life. However, treatments place a significant burden on children and their families, and are only effective if families successfully implement the prescribed plan. Unfortunately, the existing literature suggests that medical regimen adherence among children with chronic conditions is imperfect, with rates of non-adherence averaging 50% and ranging from complete non-adherence to over-adherence (e.g., taking more medication than prescribed; Rapoff, 2010). Consequently, a growing literature has focused on designing and testing interventions to improve pediatric medical regimen adherence thereby improving daily functioning, reducing treatment failure, and slowing disease progression (Dean, Walters, & Hall, 2010; Graves, Roberts, Rapoff, & Boyer, 2010; Kahana, Drotar, & Frazier, 2008; Pai & McGrady, In press; Salema, Elliott, & Glazebrook, 2011). Receiving comparably less attention is the delivery of adherence assessment and

intervention approaches in clinical practice (Wu, Pai, Gray, Denson, & Hommel, 2013). Challenges in employing evidence-based approaches include the complexity of presenting problems among clinical populations, the fast-paced nature of clinical settings, and practitioner unfamiliarity with adherence-specific clinical techniques. Thus, our goals are to review evidence-based adherence assessment and intervention strategies that can be used with youth and families in clinical practice, to illustrate the complexities of addressing adherence concerns in routine practice, and to discuss the struggles of disseminating and implementing evidence-based strategies in the real world.

Assessment

Successfully promoting adherence to pediatric regimens starts with effective assessment. There are many assessment approaches available to measure pediatric adherence, though none are perfect. Each approach has its own advantages and disadvantages and may be relevant only for some treatment components (e.g., medication, diet, airway clearance) (See Table 1). Assessment in pediatric adherence broadly can be divided into objective and subjective measures, with objective measures generally considered as more accurate. After an extensive review (Quittner, Modi, Lemanek, Ievers-Landis, & Rapoff, 2008), ten measures, spanning objective and subjective approaches, were identified as being “well-established” for the assessment of pediatric adherence. Similarly, Pai and McGrady (In press) found no difference in effect sizes for adherence-promoting interventions as a function of adherence measure (e.g., self-report, electronic monitoring) when conducting their recent meta-analysis. Thus, although we know that some measurements may be more or less accurate due to recall or desirability bias, it appears that both subjective and objective approaches have their place in measuring adherence.

One of the key difficulties in addressing pediatric non-adherence in routine practice is the relative paucity of accurate, affordable, and most importantly, *clinically feasible* measures (Haynes, McDonald, & Garg, 2002). As a result, medical providers often rely on their own judgment, despite evidence that it tends to be inaccurate (e.g., Sherman, Hutson, Baumstein, & Hendeles, 2000). We therefore need a *pragmatic* approach for clinical practice that is supported by empirical evidence. Assessing adherence first should begin with clearly defining the child’s medical regimen (Quittner et al., 2008). This may be difficult, particularly for complex medical conditions, but also because regimens tend to shift over time. Families often are not given written treatment plans (Quittner et al., 2008). As a result, clinicians should recognize that families might not fully comprehend or recall what is expected in terms of their regimen and therefore may not be a good source of information. After this step, clinicians should identify at least two methods for measuring adherence and incorporate multiple informants whenever possible (Hommel, Davis, & Baldassano, 2009; Quittner et al., 2008).

Objective Assessment Measures

One step in the assessment process includes the identification of an objective assessment strategy. For some disease groups (e.g., diabetes), this might begin with a bioassay (e.g., hemoglobin A1c levels) as a cursory screener. With bioassays, however, practitioners should consider potentially influencing factors when interpreting results, such as timing of dose,

medication pharmacokinetics, and the child's physiological characteristics (e.g., puberty; Haynes et al., 2002). For disease groups without available bioassay screening, other objective measures may be used. Electronic monitoring is one approach and is available for a variety of regimen components, including oral medications (e.g., Medication Event Monitoring System or MEMS® TrackCap), inhaled medications (e.g., Doser®, Smartinhaler®), blood glucose monitoring, insulin use (via a pump), airway clearance therapy (e.g., vest), and CPAP. Though electronic monitoring has been labeled as the “gold standard” for assessing adherence by some researchers due to its objective and detailed data (e.g., patterns of medication use), its cost and technology requirements (e.g., equipment, staff training) prohibit its widespread use within routine clinical practice (Hommel, Greenley, Maddux, Gray, & Mackner, 2013; Quittner et al., 2008). Indeed, unless reimbursed by insurance carriers, electronic monitoring usually is not available in most clinic settings. Nevertheless, the pharmaceutical and medical device industry has made some positive strides in the direction of objective monitoring, as evidenced by the inclusion of electronic monitors on standard equipment (e.g., usage data).

As an alternative to electronic monitoring, pharmacy refill data and pill counts or canister (e.g., inhaler) weights have been used as an objective index of adherence. A “medication possession ratio” (MPR) is calculated (e.g., Hess, Raebel, Conner, & Malone, 2006) and has been found to be more accurate than self-report data (e.g., Modi et al., 2006). When patients present to clinic, medical staff can contact pharmacies directly to obtain refill data over the preceding months. There are caveats to this process, however, in that paperwork (e.g., signed privacy forms), often specific to particular pharmacies, must be processed prior to receiving data (Hommel et al., 2013). Moreover, medical staff may need to speak to multiple individuals within a pharmacy before receiving approval for the release of records. Many clinics work out these details for a few cases and then establish a predictable routine from that point forward. Additional challenges in using pharmacy refill data include pharmacies charging fees for data, patients using multiple pharmacies for their medication, and families participating in automatic medication refill programs. When pharmacy refill data proves too onerous for a given clinic, pill counts and canister weights may be an alternative, indirect and objective measure of adherence. Yet, these strategies require careful record keeping and calculations by clinic staff and are reliant upon patients remembering to bring their medication to clinic appointments and not purposefully “dumping” medication prior to these visits.

Subjective Assessment Measures

Within a regular clinic appointment, the assessment of adherence might also include some form of subjective measure, such as a short, validated questionnaire or brief clinician interview. Clinicians and medical providers need to recognize concerns with the validity of self-report data and thus choose measures or approaches that maximize the veracity of information obtained. For instance, self-report data can be more accurate when patients are asked to recall adherence data over briefer intervals (e.g., previous day or week) and with respect to specific behaviors (e.g., number of doses of a particular medication) (Rapoff, 2010). In contrast, Likert-type ratings (e.g., 0 = “not adherent at all” to 10 = “very adherent”), particularly in response to a more global question (e.g., “How well have you

adhered to your cystic fibrosis regimen?”) have the potential for inaccuracy and to mask variability across different regimen components. Also, when choosing an interview or questionnaire, finding an appropriate balance between brevity and sufficient coverage of pertinent issues can be a challenge. To be clinically feasible, these instruments need to be easily administered, scored, and interpreted.

Numerous interviews and questionnaires have been developed specifically to measure adherence in pediatric populations. Although many of these measures are disease-specific, some apply across disease groups. For example, the *Medical Adherence Measure* (MAM; Zelikovsky & Schast, 2008) is a semi-structured interview, with separate modules (e.g., medication schedules, dietary restrictions) that can be flexibly selected by practitioners to assess treatment components specific to a particular disease. Another interview with broad applicability is the *24-hour Recall Interview* (Johnson et al., 1992). This interview systematically asks patients and families to recall all aspects of the child’s previous day, from which adherence information across the different regimen components is extracted. This “whole day” approach decreases the focus on adherence and thereby potentially reduces social desirability response bias (Marhefka, Tepper, Farley, Sleasman, & Mellins, 2006). The *24-hour Recall Interview* also can provide information key to intervention planning, such as insight into family routines, caregiver involvement, etc. (Marhefka et al., 2006). To enhance the validity of results, however, this interview should be administered at least three times (two week days and one weekend day) (Johnson et al., 1992; Marhefka et al., 2006). Although the interview can be delivered over a telephone, multiple administrations may pose a challenge in some busy clinic settings.

Oftentimes, standardized interviews are not feasible within fast-paced clinic settings; thus, practitioners rely upon their own ability to solicit adherence information from patients and families via a series of questions during the clinic appointment. To desensitize families to the discussion of non-adherence, it has been suggested that the topic should be broached routinely at each clinic appointment (e.g., Hommel et al., 2009). The quality of the provider-patient relationship and the provider’s communication style is key to enhancing the accuracy of self-report data within this context (Szabo, Enlow, & Duncan, 2013). Using a patient-centered approach, practitioners can phrase questions about adherence by normalizing the struggles that many patients experience and phrasing their questions to assume non-adherence. For instance, a nurse might say, “Many patients say that they find it difficult to remember their seizure medication every single day. Over the past week, how many days did you miss your pill?” Similarly, to obtain information regarding a family’s experience with barriers to non-adherence, the clinician might say, “Families have told me that they miss their medication from time to time because their schedules are too hectic and disorganized at home, or because they save money if they don’t have to refill their medication as often. What are reasons that get in the way of you taking your medication each day?” Assessing barriers (e.g., beliefs & attitudes; Drotar & Bonner, 2009) helps the clinician to ascertain whether non-adherence is intentional or unintentional – each of which would require different intervention approaches (e.g., Garfield, Clifford, Eliasson, Barber, & Willson, 2011; Graves, Adams, Bender, Simon, & Portnoy, 2007). In summary, though this communication approach does not ensure complete accuracy of self-report data, it likely

creates an empathic interaction that is more conducive to open and honest communication about adherence and related factors.

Addressing Discrepancies Between Subjective and Objective Adherence Measures

Overall, self-report (subjective) methods tend to yield good agreement between parents and children (Quittner et al., 2008), but do not correlate well with objective measures of adherence (e.g., Hommel et al., 2009). In particular, self-report data tend to overestimate adherence rates when compared to objective indices. Reasons for this overestimation may include difficulties in recalling details of adherence behavior, patient or parent poor perception of adherence difficulties, social desirability bias, or a combination of these factors (Haynes et al., 2002). Though still subjective in nature, data from diaries or self-monitoring actually converge better with electronic monitoring data than self-report (Quittner et al., 2008). So, while self-report assessment of adherence is convenient, flexible, and widely used in clinical settings, its accuracy has often been called into question.

Making significant progress toward establishing greater utility for self-report, some researchers developed an empirically based, statistical correction factor to apply to self-report data obtained from pediatric patients and families (Modi, Guilfoyle, Morita, & Glauser, 2011; Pai et al., 2012). For example, Modi and colleagues (2011) identified a correction factor of 0.83 for parent-reported adherence to pediatric antiepileptic medication. Thus, when a parent reports 100% adherence for a child, after multiplying this report by 0.83, the “corrected” adherence level would be 83%. Though these studies represent a positive direction toward enhancing the utility of self-report data in clinics, their empirical approach needs to be applied individually to various regimen components for different illness groups, preferably with a large and representative sample (to promote generalizability), to obtain relevant correction factors.

When using both objective and subjective adherence data, it is critical that clinicians and medical staff take care in how they present and address concerns that they uncover. It is not ideal to ask patients and families to report adherence, then access objective data (such as pharmacy refill information), and later report back to families the discrepancies between their report and the objective data. By doing so, families likely will feel reproved or “spied upon” and respond in a defensive manner. Rather, clinicians should use such data to facilitate open, nonjudgmental discussions with patients and families regarding barriers to adherence (Modi & Quittner, 2006; Quittner et al., 2008). Pediatric psychologists, in particular, are in a unique position to help shape and encourage positive provider-patient interactions pertaining to these situations.

Intervention

Interventions that target adherence to pediatric treatment regimens can be classified broadly as educational, behavioral, or organizational. In their recent review, Pai and McGrady (In Press) found that the majority of intervention studies were multicomponent in their approach (i.e., 96% or 22 out of 23 studies). Commonly used intervention techniques were behavioral (87%), educational (74%), and cognitive-behavioral (57%; Pai & McGrady, In Press).

Educational approaches seek to increase patient and family knowledge, skills, and recall by

providing them with information regarding the illness, its prescribed medical regimen, benefits of adherence, and possible side effects (Rapoff, 2010). *Behavioral approaches* include various techniques that target adherence behaviors, such as patient self-monitoring, setting up reminders to take medications, establishing reward or token systems, and increasing parental supervision. *Organizational approaches* typically involve changing the environment or factors outside of the patient and/or family – e.g., improving clinic access, decreasing regimen complexity.

Recent literature suggests that interventions targeting adherence to medical regimens are efficacious, with a small mean effect size ($d = 0.20$) for multicomponent interventions at post-treatment (Pai & McGrady, In Press). In addition, a meta-analysis by Graves and colleagues (2010) suggested that a combination of educational and behavioral interventions was associated with improved health outcomes (e.g., pulmonary function tests, disease severity estimates, quality of life) (Mean $d = 0.74$). Another review (Kahana et al., 2008) found medium effect sizes for behavioral (Mean $d = 0.54$) and multicomponent (Mean $d = 0.51$) approaches and small effect sizes for educational (Mean $d = 0.16$) approaches. However, transporting evidence-based interventions to clinical settings can be challenging. The following sections provide clinicians with practical guidelines on using evidence-based intervention strategies to promote adherence.

Educational Approaches

Education that is ongoing, brief, and tailored to the needs of the child may improve treatment adherence (Butz, 2006). When possible, educational programs can be conducted outside of the clinic visit so that patients and families have more opportunities to ask questions (Sandberg et al., 2006). Based on research emphasizing the importance of patient-provider communication (e.g., DiMatteo, 2006), psychologists should model and encourage patients and families to ask their medical providers questions about their treatment regimen during clinic visits. In addition, medical staff should practice treatment regimen behaviors (e.g., how to correctly use an asthma inhaler or airway clearance device), when relevant, at clinic visits to assess and address treatment-related skills (Rapoff, 2006). Clinicians also may be interested in developing educational brochures or materials for their patients, with the goal of reducing complexity and enhancing readability (Rapoff, 2010). Indeed, providing written instructions to families at each visit may be important to improve adherence (Ievers-Landis & Drotar, 2006).

Behavioral Approaches

Basic behavioral principles, such as positive reinforcement, can be used effectively in a clinical setting to improve adherence. For example, clinicians can teach parents to offer labeled praise (e.g., “I really like it when you take your medication”) for adherence behaviors (e.g., Rapoff, 2006). In addition, parents can be taught to ignore minor misbehavior (i.e., selective attention) and use re-direction (especially with younger children) related to non-adherence to regimen tasks, such as avoidance tactics (e.g., stalling) and arguing.

However, if labeled praise and/or selective attention are not sufficient to address adherence concerns, clinicians may develop a behavioral chart or reward system (e.g., Rapoff, 2010). With the support of the clinician, families can identify and define the adherence-related problem behavior (e.g., not testing blood glucose levels) and determine reasonable, specific goals. For example, if a child rarely checks his blood glucose levels, an appropriate adherence goal may be to independently monitor glucose levels once a day and then gradually increase the number of times each day over time until the regimen plan is complete. Another option would be to break the day into separate time periods (e.g., morning, afternoon, and evening) and provide rewards for adherence behavior in each time period; this approach would be particularly helpful for more complex regimens that require more than one task. Clinicians can then help families determine rewards for the earned points or tokens. Rewards for behavioral charts can include smaller daily (e.g., video game access) and larger weekly rewards (e.g., a trip to the movie theater), as well as long-term “bonus” rewards (e.g., special trip) to promote sustained adherence across time. When earned, tokens or rewards should be given immediately along with labeled praise. In addition, the behavioral chart should be visible to children (e.g., on the refrigerator) and children ideally should take an active role in completing it. For older children and adolescents, using behavioral contracts may be more appropriate than behavioral charts. Contracts involve negotiation between the youth and caregiver, outlining specific responsibilities and consequences (Rapoff, 2010).

Although families usually prefer positive reinforcement methods, strategies such as response cost (e.g., time-out, loss of privileges, token economy with point loss) may be an alternative for children who are not responding to a positive reward system (Rapoff, 2010). With this approach, non-adherence “costs” children the opportunity to enjoy parental attention, rewards, or activities that they enjoy. Like behavioral charts and reward systems, it is important that families have clearly specified expectations and consequences and that families follow-through with these consequences.

Simple changes to a family’s home environment also may improve adherence to medical regimens. For example, using visible reminders (e.g., pill boxes, notes on a bathroom mirror) may help address forgetfulness. Setting alarms on cellphones or watches may be another practical solution for reminding some families. Furthermore, pairing adherence behaviors with already established daily activities (e.g., meal time, brushing teeth) might help to enhance adherence (Rapoff et al., 2002).

Some patients may not be motivated to be adherent to their medical regimens, despite use of positive reinforcement and routines. If this is the case, it is important to convey to families that adherence setbacks are normal (Drotar et al., 2006). In addition, motivational interviewing techniques (e.g., Riekert, Borrelli, Bilderback, & Rand, 2011) may help increase motivation for families. For example, inquiring about a child’s confidence in his or her abilities to improve adherence and then evaluating how the child can become more confident may highlight areas that then can be targeted by the clinician. It also may be useful to set small goals initially that are achievable and have a high likelihood of success with patients that are questioning their abilities or motivation to be adherent. This may not only

improve confidence in their abilities to be adherent to their regimen (Harris et al., 2013), but also lead to the experience of positive health outcomes.

Indeed, studies suggest that providing children and their families with graphs or feedback on how their adherence behavior influences health outcomes (e.g., showing pulmonary function graphs) may be reinforcing and improve adherence. For example, using a single-subject design, Spaulding and colleagues (2012) found that adherence improved when patients with asthma were given feedback (i.e., electronic monitoring data for inhaler use) by medical staff, especially in those who had low baseline adherence. If possible, using objective adherence monitoring techniques (e.g., dose counters on inhalers, MEMS® TrackCaps) may be a relatively practical method for providing families with feedback on their adherence behaviors or the effectiveness of adherence-promoting strategies (e.g., token system). If objective measures are not available, simply encouraging families to track adherence at home (e.g., using a calendar posted on the refrigerator; counting pills) may be a useful alternative.

Behavioral approaches also may be most effective when targeting the whole family. For instance, clinicians can help families work together to cope with adherence-related conflicts. Increasing cooperation and sharing of adherence responsibilities may be beneficial for families (e.g., Anderson, Brackett, Ho, & Laffel, 1999). Parental supervision can be faded as children take more responsibility for their medical regimen tasks and demonstrate an ability to maintain adherence. As an example, in a randomized clinical trial, Duncan et al. (2013) found significantly greater mean daily adherence (i.e., at least 80% across 5 months) to preventive inhaler use in youth with asthma who participated in an intervention that emphasized shared parent-youth responsibility and fading of parental involvement as adherence goals were achieved. Another general strategy that can be used includes problem-solving approaches to help families become experts at identifying and solving adherence-related problems. In a preliminary study, Modi, Guilfoyle, and Rausch (2013) found that families who participated in a problem-solving intervention demonstrated improved adherence (mean percent change from baseline to post-treatment = 31.5) compared to families in a treatment as usual group (mean percent change = 9.3). This type of intervention may be used with children of all ages. For instance, adolescents may be instrumental in coming up with possible solutions to the problem while younger children may come up with possible rewards for solutions that are effective in managing their adherence-related concerns (Modi et al., 2013).

Finally, given the complexity of some cases that present to clinical settings, it may be necessary to refer the child or family for individual psychotherapy or family therapy if the strategies described above fail to address the adherence concerns or if there are larger challenges (e.g., severe family conflict, mood issues) that need to be addressed first.

Organizational Approaches

Perhaps often overlooked, organizational aspects of clinical care should be considered when addressing adherence concerns. Clinic settings that are welcoming, organized, and patient-friendly may improve the likelihood that patients not only return for their follow-up appointments, but also follow their prescribed treatment regimen (Rapoff, 2010). Whenever

possible, the same physician should see a patient across clinic visits to maintain continuity of care (Rapoff, 2010). Medical staff also should take the time to review the treatment plan effectively with families at each clinic visit (Levers-Landis & Drotar, 2006) and provide an easy-to-understand written summary for families to take home.

Another organizational approach is to reduce the complexity and costs of the treatment regimen when possible (Winnick, Lucas, Hartman, & Toll, 2005). Because the expense of the treatment regimen may be a significant barrier to adherence for some families, reducing cost alone may be effective in enhancing adherence. Similarly, a psychologist could work with the provider and family to identify ways to reduce the burden of a regimen, perhaps by decreasing the number or modifying the timing of medication doses.

Summary

It is important to keep in mind that one approach most likely will not work for all patients and that families may require different strategies over time; rather, it is necessary to evaluate and address patient- or family-specific barriers to adherence to tailor intervention strategies. Adopting a “tool box” approach (Cortina, Somers, Rohan, & Drotar, 2013), in which clinicians adapt an intervention to meet the patient’s needs and draw from multiple strategies described above, may be more appropriate when working in clinical settings. Furthermore, with society’s increased use of technology in day-to-day activities, practitioners should seek opportunities to integrate such technology into their adherence-promotion strategies when families are amenable to this approach (Dayer, Heldenbrand, Anderson, Gubbins, & Martin, 2013). For example, MangoHealth (<http://www.mangohealth.com/products>) provides users with reminders to take their medications, allows individuals to earn “points” leading to raffled rewards when they report taking their medication(s), and tracks users’ adherence progress. Finally, a major goal of clinicians working with patients to improve adherence should be the maintenance of treatment effects. However, studies suggest that the effects may only last during the intervention phase (i.e., while the clinician is actively targeting adherence behavior; Cortina et al., 2013). Indeed, a recent meta-analysis (Pai & McGrady, In press) found a small effect size for maintenance of treatment effects in studies that provided follow-up data ($d = .29$). Therefore, it is important for clinicians to schedule booster sessions and increase patient contact within medical settings whenever possible, as well as continue to assess and address adherence across time.

Case Study

The following case study illustrates the use of evidence-based assessment and intervention to promote adherence in a real world setting. “Gina” was a 17-year-old African-American female recently diagnosed with end stage renal disease. Given her challenges with medical regimen adherence (i.e., nausea and emesis related to medication taking) and emotional functioning (i.e., anxiety), the renal transplant team referred her to Pediatric Psychology for evaluation and treatment prior to activating her on the transplant waitlist.

Gina was on home peritoneal dialysis and was prescribed 10 different medications administered on variable schedules. She had the most difficulty taking her iron and calcium pills three times per day with meals. Gina was also required to monitor her blood pressure

daily and to meet particular dietary goals. Due to eating meals at irregular times and her reported food aversions, Gina had significant difficulty adhering to her regimen. Gina's parents were also concerned about her depressed and anxious mood, and their perception that she was not motivated to be listed for transplant.

Several measures and informants provided information on Gina's adherence. First, Gina's self- and parent-reported adherence to her medication regimen and diet were assessed using the *Medical Adherence Measure* (MAM; Zelikovsky, Schast, Palmer, & Meyers, 2008). Second, the severity of Gina's reactions to oral intake was assessed using biofeedback during medication administration and presentation of various foods. Gina had significant physiological changes in her peripheral temperature, heart rate, and breathing when presented with her pills and food. She gagged and turned her head away, refusing to accept anything by mouth. Third, Gina's potassium and phosphorus levels obtained via blood draw were used as markers of medication and dietary adherence. Fourth, home-based assessments were used, including electronic monitoring of the home dialysis machine, review of Gina's daily logs of home blood pressure readings and time spent in dialysis, and home visits from the nephrology nurse to assess the environment for barriers to adherence.

A multimodal intervention approach was employed to improve Gina's adherence through educational, behavioral, and organizational strategies targeting pill swallowing, self-monitoring, and reduction of depression and anxiety symptoms. Gina attended outpatient therapy sessions with the pediatric psychologist every two weeks, and had check-in appointments with the medical team on alternating weeks to review her adherence and medical outcomes (e.g., laboratory values). The pediatric psychologist employed stimulus-fading strategies to address Gina's difficulty swallowing pills, beginning with small practice pills (i.e., candy sprinkles) and progressing to practice pills closest in approximation to Gina's actual medications. Pill swallowing training was modeled in session, and Gina was differentially reinforced for her cooperation and eventual swallowing of the pills within the allotted time frame (< 5 minutes). During in vivo sessions, the patient was monitored using biofeedback sensors, and was encouraged to use diaphragmatic breathing. The patient practiced pill swallowing at home, and video recorded these trials for review at future face-to-face sessions. A similar strategy was employed to increase the patient's acceptance of a wide variety of foods. Gina was also provided with education related to self-monitoring via the use of weekly medication tracking sheets (www.MyMedSchedule.com) and a SmartPhone application to track her food intake. Gina also set her cell phone alarm to prompt medication administration. In addition, Gina was instructed in cognitive-behavioral coping skills training, including relaxation training, pleasurable activity scheduling, and cognitive restructuring. These activities focused on maladaptive thoughts related to pill swallowing (i.e., "that pill is nasty and will make me puke for sure") as well as the transplant process (i.e., "what if after all of this, I reject someone else's kidney?").

Gina was seen for a total of 30 visits over 13 months. During this time, she significantly improved her medication and dietary adherence, as evidenced by laboratory values, self-report and weight gain and maintenance. Gina continued to use cellphone alarms to prompt administration. Her mood dramatically improved, and she enrolled in college classes and obtained employment. She expressed interest in being activated on the transplant waitlist

and expressed hopefulness about her future. Given significant and sustained improvements in her adherence, she was activated on the transplant wait list. She was transferred to the adult nephrology service at the same institution, and continued to have phone follow-up with the pediatric psychologist. She subsequently underwent transplantation with a deceased donor kidney, and is medically and psychosocially stable with no identified barriers to adherence.

Dissemination

Despite the availability of assessment and intervention tools, there are significant barriers to the implementation of these strategies in clinical practice (Gallo & Barlow, 2012; Lilienfeld, Ritschel, Lynn, Cautin, & Latzman; Wu et al., 2013). A recent study implemented by the Dissemination subcommittee of the Adherence Special Interest Group (SIG) of the Society of Pediatric Psychology (SPP; Division 54 of the American Psychological Association) examined current clinical practices in adherence within the field of pediatric psychology. Specifically, this study evaluated pediatric psychologists' use of adherence assessments and interventions, including barriers and facilitators within clinical practice (Wu et al., 2013). In total, 113 SPP members who participate in clinical care and/or supervision completed a survey focused on clinical practice and research in adherence or self-management. With respect to assessment measures, approximately 70% of respondents reported using at least one type of adherence measure in clinical practice. The most frequently used assessment strategies included clinical interviews conducted with the patients and/or parents, while structured self-report measures were used least often. Similarly, disease-specific measures were not commonly used in clinical practice. Regarding intervention practices, nearly 70% of respondents endorsed use of at least one intervention strategy to address adherence and/or self-management.

The results of this survey (Wu et al., 2013) were consistent with the literature, which recommends taking a multi-component approach to the promotion of adherence (Graves et al., 2010; Kahana et al., 2008). Yet, study respondents cited frequent barriers to the implementation of evidence-based practice (EBP) in clinical settings. The majority of respondents provide clinical care as part of a multidisciplinary treatment team, and reported that time constraints frequently impeded their ability to treat medication adherence. In addition, study participants indicated that they seek information regarding adherence assessment and intervention strategies from a range of peer-reviewed journals and peer consultation, followed by books, workshops and the Internet. Despite the fact that most respondents indicated using at least three sources to guide their clinical practice, nearly 85% stated that they would benefit from learning ways to enhance their implementation of adherence assessments and interventions. In fact, many respondents cited lack of familiarity with evidence-based strategies as frequent barriers in clinical practice. There is clearly a gap in the translation of research findings into clinical practice that could potentially be ameliorated by making EBP more readily accessible to practicing pediatric psychologists.

In general, psychologists are receptive to the premise of integrating EBP in clinical settings, yet, the dissemination and implementation of these strategies has been slow. Across psychology disciplines, a major source of resistance to implementing EBP relates to

pragmatic challenges, with time limitations being a primary barrier (Gallo & Barlow, 2012). Remaining current on the latest evidence, research findings, and professional guidelines is a time intensive process, particularly if clinicians are unaware of where to access relevant resources. Being a successful adopter of EBP requires practitioners to have time to read and interpret research studies and subsequently apply these findings to their clinical practice. Clinicians may find it difficult to translate the well-controlled, narrowly defined studies into the real world scenarios they typically encounter in their practice (Berke, Rozell, Hogan, Norcross, & Karpiak, 2011; Gallo & Barlow, 2012). Indeed, the majority of randomized clinical trials examining the efficacy of adherence promoting interventions in pediatric populations did not specifically target patients with identified adherence difficulties (Pai & McGrady, In press). In contrast, in clinical practice, the children and adolescents with significant non-adherence are typically those who are referred for intervention. Thus, further work is needed to apply research-based interventions that have been tested with adherent populations to “clinically representative” populations with complex adherence difficulties.

To overcome the challenges associated with dissemination of EBP, there are several recommendations. Researchers are urged to publish their study findings in a manner that effectively communicates the benefit. Moreover, pediatric psychologists are encouraged to publish case reports from clinical practice that focus on non-adherence among children and adolescents with a range of chronic health conditions and comorbidities that may not be well represented in published randomized clinical research trials (Cortina et al., 2013). The journal of *Clinical Practice in Pediatric Psychology* has established guidelines for writing case reports (Ernst et al., 2013), which provide an opportunity to present examples of the implementation of EBP with difficult real-world cases. The Society of Pediatric Psychology also has established an EBP resource library to provide clinicians and researchers with accessible information, skills, tools and a summary of the evidence for pediatric psychology assessments and interventions (<http://www.apadivisions.org/division-54/evidence-based/index.aspx>).

In addition to encouraging clinicians to implement EBP in their assessment and promotion of adherence, it is also recommended that pediatric psychologists participate in the training of other health care providers (i.e., nurses). As many pediatric psychologists are integrated into multidisciplinary teams, this may allow for the opportunity to provide education regarding the types of assessments and interventions psychologists use to promote adherence. Training should include a theoretical framework that underlies adherence intervention as well as guidance in the delivery of evidence-based interventions (Rapoff, 2002, 2013). Pediatric psychologists may provide this type of education through formal workshops or grand round presentations, as well as informal education through clinical rounds and team meetings. Moreover, in academic settings, pediatric psychologists may be in a position to participate in medical student and resident education, which would allow for an introduction to adherence assessment and intervention strategies. Partnering with medical providers may allow for effective interventions to be incorporated into clinical settings more readily. In addition, this may also encourage medical providers to make appropriate referrals when regimen non-adherence is the presenting concern (Wu et al., 2013).

Dissemination and implementation (D&I) research offers another potential tool as the field of pediatric adherence promotion progresses. D&I research seeks to identify mechanisms to increase the speed of EBP dissemination into practice settings, and to optimize psychosocial treatments for multiple contexts (Institute of Medicine, 2001). Two stages in D&I research that have received the most attention: (a) transportability, which is focused on the processes involved in moving evidence-based treatment from research into community setting; and (b) dissemination studies, which focus on how to distribute the treatment and its training/support “package” (Southam-Gerow & McLeod, 2013). D&I research shifts focus away from primary clinical outcomes, and methods needed to implement a treatment in a new setting is the central focus. Specifically, D&I research places emphasis on assessing treatment integrity, to determine if lack of desired clinical outcome is related to the EBT or to the implementation. Building on the D&I philosophy, adherence assessment and intervention strategies should be developed with clinical application in mind (Chorpita & Nakamura, 2004; Glasgow, Magid, Beck, Ritzwoller, & Estabrooks, 2005) and tested in real-world settings to determine the effectiveness of adherence assessment and intervention strategies employed in clinical practice.

Future efforts focused on implementation science and practice-based evidence is essential for pediatric adherence promotion. However, patient needs for adherence support do not go unmet while practitioners wait for sufficient research guidance. Rather, practitioners in the real world often use available resources and knowledge to develop innovative strategies (e.g., technology-based) to support their patients. Increasingly, technology-based interventions, such as video-conferencing, text-messaging, and web-based interventions, are being used to promote medication adherence while addressing barriers, such as time and access to services (Stinson, Wilson, Gill, Yamada, & Holt, 2009; Cushing & Steele, 2010; Linn, Vervloet, van Dijk, Smit, & Van Weert, 2011). The use of the Internet, cellphones and text messaging is ubiquitous among all socio-economic groups (Madden et al., 2013), making technology a potentially viable and effective mechanism for disseminating evidence-based interventions.

To further examine barriers to dissemination, research should focus on practitioners’ decision-making regarding the use of EBP clinical practice. Specifically, research could examine how practitioners select assessment measures (i.e., interview, standardized measures), intervention strategies (e.g., problem-solving, motivational interviewing), and delivery mechanisms (e.g., in-person, video-conference, text messaging) in the context of a busy clinical practice. In addition, research should identify how pediatric psychologists incorporate and promote use of adherence assessments and interventions within multidisciplinary treatment teams.

Conclusion

A variety of evidence-based adherence assessments and interventions are available to pediatric psychologists and other healthcare providers working in clinical settings. The tools reviewed in this manuscript vary by their accessibility to practitioners, the level of training required to implement them, and the amount of time they take to administer. As reviewed in the previous section, there are many barriers to using EBP for adherence in clinical practice.

Perhaps most significant are resource limitations, including unfamiliarity with available tools and time limitations in clinical practice.

Future directions for addressing these barriers include increasing dissemination of materials focused on clinical application in the published literature (e.g., case reports to illustrate the use of adherence interventions), creating publicly-available resources for adherence materials (e.g., resource libraries that summarize clinical applications of adherence assessments and interventions), introducing professional education opportunities for adherence assessment and interventions (Wu et al., 2013), and using D&I research. Examples of successful dissemination strategies can be found in the clinical child and general clinical psychology literatures (McHugh & Barlow, 2011; Nakamura et al., 2011). As the field of adherence assessment and intervention matures, it will be important to develop evidence-based tools that are practical and can easily be translated into practice. For instance, tools that are time efficient, can be tailored to individual patient need, and can be useful for multidisciplinary treatment approaches (Wu et al., 2013) will be more likely to be used in practice. One way to ensure that clinical needs are taken into account throughout the development and research process is to foster partnerships between clinicians and researchers throughout the development process (e.g., Southam-Gerow, Hourigan, & Allin, 2009).

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Table 1

Summary of Assessment Methods for Adherence to Pediatric Regimens

Objective Methods
<u>Bioassays</u>
<p><i>Advantages</i></p> <ul style="list-style-type: none"> • Can be used with blood, urine, or saliva • Measures medication consumption (e.g., antiepileptic drugs) or therapeutic outcomes of treatment (e.g., hemoglobin A1c with diabetes, viral load suppression with HIV) • Can be part of routine clinical care (especially if reimbursed) <p><i>Disadvantages</i></p> <ul style="list-style-type: none"> • Not available for some medications or relevant to particular regimen components (e.g., airway clearance with cystic fibrosis) • Results may be affected by dose, timing, pharmacokinetics, and drug metabolism factors • May not be sensitive enough to detect occasional (minor) non-adherence • Does not provide information (e.g., patterns of non-adherence) that could inform treatment • Has potential to be manipulated by patient (e.g., by dosing before appointment)
<u>Electronic Monitoring</u>
<p><i>Advantages</i></p> <ul style="list-style-type: none"> • Has potential to measure a variety of adherence behaviors such as timing of dose/check (e.g., glucose), technique (e.g., with inhalers), which provides insight into medication taking patterns for treatment planning purposes <p><i>Disadvantages</i></p> <ul style="list-style-type: none"> • Usually does not measure actual consumption of medication (e.g., MEMS™ cap measures opening a bottle) • Complex to use (e.g., training required for software & equipment) • Is costly (e.g., devices, equipment, web access fees) and most are not reimbursed by insurance (except for blood glucose monitors & insulin pumps for diabetes) • Is not compatible with all medications (e.g., large pills) and does not apply to certain regimen components (e.g., dietary adherence) • Associated with technological issues such as battery failure and malfunction (e.g., inhaler monitor registering use as the result of being shuffled within a child’s backpack) • May not be acceptable to patients and families
<u>Pharmacy Refill Data</u>
<p><i>Advantages</i></p> <ul style="list-style-type: none"> • Generally inexpensive (though some pharmacies may charge fees for records) • Fairly accurate (correlates significantly with electronic monitoring data) <p><i>Disadvantages</i></p> <ul style="list-style-type: none"> • Does not measure consumption • Need to consider possibility of patients using other pharmacies, stockpiling medications, or using family members’ medication • Logistics (e.g., staff time, privacy regulations) to obtain records may be difficult • Will not be applicable if patient’s medications are refilled automatically
<u>Pill count/Canister Weight</u>
<p><i>Advantages</i></p>

Objective Methods
<ul style="list-style-type: none"> • Inexpensive • Fairly accurate (correlates significantly with electronic monitoring data) <p><i>Disadvantages</i></p> <ul style="list-style-type: none"> • Patients may forget to bring their medication to clinic or miss their appointment • Has potential to be manipulated by patient (e.g., dump medication prior to clinic appointment) • Does not confirm that medication was ingested • Can be cumbersome for staff to collect & calculate
Subjective Methods
<u>Interviews</u>
<p><i>Advantages</i></p> <ul style="list-style-type: none"> • Can obtain information on a variety of regimen components, not just medication use • Has potential to provide information on related issues, such as family routines, that could be useful for treatment planning • Some can be administered over the telephone, as well as in clinic <p><i>Disadvantages</i></p> <ul style="list-style-type: none"> • Relies on self-report; subject to recall bias • Accuracy depends on the psychometric properties and structure of the interview
<u>Diary/Self-Monitoring</u>
<p><i>Advantages</i></p> <ul style="list-style-type: none"> • Reduces demands on memory • Inexpensive • Flexible; can be devised to monitor a range of variables (e.g., timing, duration) in relation to a variety of adherence components (e.g., diet, medication use, physical exercise) <p><i>Disadvantages</i></p> <ul style="list-style-type: none"> • Relies on self-report; has potential to be fabricated by patient, perhaps due to social desirability • Requires “adherence” to recording information, when adherence is a general concern
<u>Questionnaires</u>
<p><i>Advantages</i></p> <ul style="list-style-type: none"> • Inexpensive • Convenient & relatively unobtrusive; can be administered during wait time & reviewed by clinic staff during appointment <p><i>Disadvantages</i></p> <ul style="list-style-type: none"> • Relies on self-report; subject to bias & social desirability • May mask variability of adherence across regimen components if assessed globally

Sources: Garfield et al., 2011; Haynes et al., 2002; Hommel et al., 2008; Hommel, Mackner, Denson, & Crandall, 2013; Marhefka et al., 2006; Quittner et al., 2008