REVIEW

Diabetes Management

Adherence in adolescents with Type 1 diabetes: strategies and considerations for assessment in research and practice

Kajal Gandhi[1], Bach-Mai K Vu[1], Sahar S Eshtehardi[2], Rachel M Wasserman[2] & Marisa E Hilliard*[,2]

Practice points

- Greater adherence to self-management tasks predicts better diabetes health outcomes, yet barriers are extremely common.
- Hemoglobin A1c is not an adequate proxy biomarker of adherence, given numerous other influences on glycemic control. Thus, the lack of a reliable biomarker of adherence compels us to rely on measures of diabetes management behaviors to assess adherence.
- Measurement of adolescents' Type 1 diabetes (T1D) adherence is complicated by the multiple behaviors that comprise the individualized T1D regimen and the need to evaluate adherence behaviors of multiple people, including parents/caregivers.
- Objective measures are preferred over subjective due to decreased risk for response bias, and include electronic data from blood glucose monitors or insulin pumps to assess the frequency and timing of specific diabetes management behaviors.
- Subjective measures are commonly used and include questionnaires, structured interviews and logbooks or diaries in which reporters rate their impressions or recollections of adherence behaviors in the past. Given potential downsides (e.g., recall or response biases, limited utility for people with low literacy or English proficiency), subjective measures are most appropriately used when there are no feasible objective measures of adherence available, or as a supplement to objective measures.
- In clinical settings, assessment of adherence can inform treatment considerations and identify patients who may need behavioral interventions or social supports to improve adherence and ultimately clinical outcomes.

Suboptimal adherence remains a significant concern for adolescents with Type 1 diabetes, the treatment regimen for which is complex and includes numerous behaviors. Accurate assessment of adherence is critical for effective healthcare and to measure trial outcomes. Without a valid biomarker of adherence, assessment strategies must rely on measuring management behaviors. This paper provides an overview of approaches to measure adherence, with an emphasis on contemporary, validated measures that are appropriate for current diabetes care. Objective measures include electronic data from diabetes

[1]Section of Pediatric Diabetes & Endocrinology, Department of Pediatrics, Baylor College of Medicine, 6701 Fannin Street, Suite 1020, Houston, TX 77030, USA
[2]Section of Psychology, Department of Pediatrics, Baylor College of Medicine, 1102 Bates Avenue, Suite 940, Houston, TX 77030, USA
*Author for correspondence: Tel.: +1 832 824 7209; Fax: +1 832 825 1222; marisa.hilliard@bcm.edu

Future Medicine part of fsg

management devices. Subjective measures include self/parent-report questionnaires, structured interviews and diaries/logbooks. Practical strategies for selecting measurement approaches for clinical and research purposes are reviewed, and implications of adherence assessment for clinical care delivery and adherence-promotion are discussed.

KEYWORDS
• adherence • adolescence • assessment • research methods • Type 1 diabetes

Despite recent advances in treatment strategies and technology, adolescents with Type 1 diabetes (T1D) have poorer glycemic control and higher rates of acute complications than adults [1]. Moreover, treatment adherence and glycemic control are known to deteriorate substantially across adolescence [2,3]. Suboptimal outcomes during adolescence confer increased risk for long-term complications, even for individuals whose glycemic control subsequently improves in adulthood [4,5].

Greater adherence to evidence-based management recommendations consistently relates to better clinical T1D outcomes. A meta-analysis of 21 studies and 2429 adolescents showed that higher adherence predicts better glycemic control independent of various indices of sociodemographic status (e.g., socioeconomic, minority race/ethnicity, single parent caregiver) [6]. Adolescents who demonstrate better adherence – for instance, more frequent BGM and premeal insulin administration – have better glycemic control and fewer acute complications than youth who engage in these behaviors less frequently [7,8]. Thus, accurate measurement of adherence behaviors is critical for research and clinical care that aims to promote optimal health outcomes.

The goal of this paper is to provide a practical overview of approaches for measuring adherence to treatment recommendations among adolescents with T1D. First, conceptual considerations and definitions of adherence are reviewed. Next, characteristics of specific assessment instruments will be reviewed. Finally, practical strategies for selecting measurement approaches for clinical and research purposes are discussed.

Conceptual issues in adherence

Adherence refers to "the extent to which a person's behavior coincides with medical or health advice" [9]. Among youth with T1D, such advice or treatment recommendations include a combination of frequent blood glucose monitoring (BGM), calculating insulin requirements, administering insulin and/or glucose as needed, possible medication administration, careful attention to diet (e.g., counting carbohydrates for insulin:carbohydrate ratios) and exercise, clinic attendance, obtaining prescribed laboratory studies and maintaining medical supplies [10–12]. The burden of adhering to these various behaviors is carried by adolescents and their families and affects nearly every aspect of daily life. Barriers to optimal treatment adherence are common and include competing demands for time and attention, miscommunication or misunderstandings about what to do (among family members and between families and healthcare providers), financial or insurance-related barriers to obtaining needed care/supplies, insufficient adult involvement or monitoring of adolescent self-management and emotional or behavioral difficulties, among others [7,13].

The term 'adherence' is used in contemporary medical literature because it communicates the importance of viewing people with diabetes as empowered and active participants in their own healthcare. It is preferred over 'compliance,' a term dating from a more paternalistic era of medicine in which people were expected to obey or accede to prescribers' directions [14]. 'Self-management' is a related neutral term representing the processes by which people execute health behavior recommendations [9].

Challenges in assessing adherence in adolescents with T1D

Assessing and monitoring adherence are important parts of routine diabetes clinical practice, but several unique features of T1D present challenges. First, in contrast to conditions requiring a single care behavior (e.g., once- or twice-daily oral medication), the complexity of T1D management recommendations require that adherence to multiple behaviors be considered. There may be distinct facilitators of or barriers to each self-management behavior, and individuals tend to not be uniformly adherent to all behaviors [15]. Indeed, adherence to simple tasks such as pill-taking tends to be higher than more complex tasks [16], such as BGM or insulin calculations, which are central to T1D management. Little evidence exists on the comparative clinical consequences of nonadherence to particular behaviors.

Second, T1D management regimens are neither universal nor static, so clinicians and researchers interested in measuring adherence must first determine: adherence to what?

Advances in science and technology offer a variety of choices with regard to insulin types, delivery devices including pens and pumps, and glucose checking tools such as meters and continuous glucose monitors. Strict adherence to particular behaviors of a typical T1D regimen may not be feasible for some people (e.g., athletes, youth with developmental delays or other chronic conditions), requiring modifications. Additionally, insulin regimens or delivery methods may need to be tailored depending on individual needs (e.g., higher insulin requirement due to illness or puberty), activities (e.g., sedentary days versus sports activities), abilities of different caregivers (e.g., school nurses) or changing schedules (e.g., traveling, attending summer camp). These may be long-term changes that occur gradually (over months or years) or short-term adjustments to address a temporary (hours, days or weeks) need, adding to the challenge of monitoring adherence over time. Because the determination of adherence rates requires a mathematical calculation of the frequency of behaviors that are executed compared with the frequency of behaviors prescribed [6], changing recommendations make it difficult to establish a denominator (i.e., the recommended behavior frequency) and accurately calculate an adherence rate.

Furthermore, adolescents generally are not the sole managers of their diabetes. Primarily parents – but also other family members, teachers, coaches, school nurses, and friends – also provide support and execute many diabetes management tasks, so there is a need to evaluate adherence behaviors of multiple caregivers. As adolescents' capacities and desire for autonomy grow, responsibility for diabetes management tasks may shift between parents and youth. However, the timing, pace and success of this process varies [17] and is influenced by many factors including adolescents' cognitive development, emotional well-being, attitudes and beliefs about self-management and the emotional tone and degree of collaboration in parent–adolescent interactions around diabetes management [18–22]. Supporting successful transition to self-management is a major goal of the care of adolescents with diabetes [10], so clinically relevant measures of adherence ideally should help clinicians understand youth and families' experiences as they move toward achieving self-management milestones.

Finally, the lack of a reliable biological measure of adherence, such as drug levels in blood, compels us to rely on measures of diabetes management behaviors themselves in order to assess adherence. Although many measures of adherence have been developed for a variety of chronic diseases, there remains no gold standard measure of T1D adherence [23]. The remainder of this paper is an updated and practical review of contemporary approaches for assessing adherence among adolescents with T1D.

Considerations in selecting a measure

There are numerous options for assessment of adherence in adolescents with T1D, each with benefits and costs to be considered **(Table 1)**. Depending on the specific adherence information needed, a measure with the appropriate degree of comprehensiveness and breadth or specificity and depth should be selected. For survey or interview instruments, other considerations include whose report – youth/self, parent or provider – will be measured and the period of time about which they will be reporting. Measures of adherence behaviors must be validated and have clinical relevance, making the psychometric properties of central importance. Psychometric considerations include item, scale and total score reliability; various measures of validity: construct (association with measures of similar constructs), discriminant (association with measures of dissimilar constructs) and criterion (association with key clinical outcomes); and sensitivity to change [23,24]. Depending on the purpose, it may be useful to select additional measures that assess related constructs and contributors/barriers to adherence, such as motivations, beliefs and resources. All of this should be considered within the context of logistical resources, including time and personnel resources needed to complete, score and interpret the measure; licensing costs; assessment method (e.g., telephone, in person, online); and validation of the measure in the appropriate age range and language [24].

Methods & measures for adherence assessment

Adherence can measured through objective and subjective methods – objective measures assess the occurrence of a behavior, while subjective measures assess an individual's report of whether a behavior occurred – each will be reviewed below.

• Objective adherence measures

When available, objective measures are preferred over subjective, because less reporter bias

Table 1. Considerations for type of adherence measurement.

Measure	Benefits	Considerations
Direct, objective methods		
Blood glucose meter download	Objective data about occurrence of BGM events over many days Collected routinely in many clinics Unobtrusive to patient Multiple ways of calculating BGM adherence: – Frequency (average over last 14 days) – Consistency/variability across days – Timing	Need to access all meters to calculate true adherence rate, relies on patient to bring all meters Risk of inaccuracy in meter's internal clock/calendar If unable to download, manual recording can introduce error Measure of BGM only (no insulin-related behaviors) Downloading and interpreting data can be time-intensive
Pump download	Objective information about insulin administration events Collected in clinic Unobtrusive to patient Algorithms exist to guide calculation of insulin administration (e.g., BOLUS score)	Pump date/time could be inaccurate If unable to download, manual recording could introduce error Measure of insulin administration via pump only; does not account for any insulin administered via pen/injection Other information (e.g., manually entered glucose values, carbohydrate intake) is subjective Downloading and interpreting data can be time-intensive
Indirect, objective methods		
Pharmacy claims (prescription fills/refills)	Objective information about frequency of refilling prescriptions/supplies Indirect measure; can infer rate at which BGM and insulin are used through rate of refills	Not previously used with youth with T1D Relies on an assumption that patients use the prescriptions they fill
Hemoglobin A1c (not recommended)	Measure of glycemic control, which is related to adherence	Does not measure adherence because A1c is influenced by numerous other variables (e.g., metabolism, puberty, stress) outside of just adherence behaviors
Subjective methods		
Self-report questionnaire	Can assess several adherence behaviors at a time Length is adjustable depending on provider's preference and need Scores on validated measures may be easily compared across studies/samples	Dependent on respondent perception and recall Potential for biased responding (e.g., social desirability bias; effects of depressive symptoms) Burden lies with respondent to complete questionnaire May cost money to administer Need to consider validation of measure, how the measure has been used previously, language and age range
Parent-report questionnaire	Can assess several adherence behaviors at a time Length is adjustable depending on provider's preference and need Scores on validated measures may be easily compared across studies/samples	Parent may not observe all adherence behaviors completed by child Dependent on parent's perception and recall Potential for biased responding (e.g., social desirability bias) Burden lies with respondent to complete questionnaire May cost money to administer Need to consider validation of measure, how the measure has been used previously, language and age range
Interview	Can assess several adherence behaviors at a time May be more flexible than a questionnaire May obtain more detailed information about adherence behaviors	Time consuming for staff and respondents Requires trained interviewer to administer, score, interpret Risk for low fidelity to interview guidelines Responses are dependent on perception and recall

Table 1. Considerations for type of adherence measurement (cont.).

Measure	Benefits	Considerations
Provider report	Can assess several adherence behaviors at a time No additional burden on youth or parent	Risk for poor validity due to: – Provider does not directly observe many adherence behaviors – Poor communication about adherence with youth/parent – Assumptions about adherence based on knowledge of family environment, race, age, current health status/glycemic control and other factors other than actual adherence behavior Time burden on provider
Logbook/pump Diary Download	Can assess several adherence behaviors at a time Reduced recall period (usually <1 day) May provide more information about specific events (e.g., hypoglycemia)	Information may be inaccurate: – Patients may fill them out all at once rather than each day – Responses may be biased (e.g., social desirability bias, "white coat adherence") Time burden on respondent

is introduced [23,24]. Objective measures can further be classified into direct and indirect methods.

Direct objective methods

Direct methods include observations of the target behavior. This is difficult to implement in routine clinical research or practice, as it would require live or recorded observations over many hours or days to capture the numerous tasks of diabetes management as they occur. As an alternative, electronic recordings of adherence behaviors through diabetes management technologies are becoming increasingly accessible and well-accepted [25,26].

BGM adherence via meter download

One frequently used measure of adherence is the frequency of BGM; extracting BGM event data from blood glucose meters (either through electronic download or manual transcription) is a common strategy for direct objective measurement of this behavior [26]. Blood glucose meters typically store data for several weeks or months. In addition to providing summary reports of glycemic values (e.g., blood glucose excursion patterns, average daily glucose values), meter data can also be used to assess adherence to BGM recommendations: the date and timestamp that are recorded each time the person uses the meter permit calculation of the daily rate of BGM events [25,27]. Newer meter software allow data to be downloaded to local or cloud-connected websites, allowing remote access by providers or investigators [25].

While greater BGM frequency as measured by self-reported estimates and glucose meter downloads both have strong associations with better glycemic control [3,28], the direct, objective data from electronic meter downloads are more robust and reliable predictors of diabetes outcomes [27]. As automated BGM technologies (e.g., continuous glucose monitoring [CGM] devices, see below) continue to advance and become more ubiquitous, assessing BGM frequency using meters may eventually become less relevant or less representative of overall adherence.

CGM devices

As a note, CGM devices are a relatively new technology that automatically measure and report real-time trends in glucose (e.g., rapidly dropping, slowly increasing) [7,29]. While CGM devices do require some manual BGM for calibration and insulin decision-making, the data they produce do not capture BGM frequency and therefore cannot be used to measure adherence [23].

Insulin adherence via pump download

Similar to blood glucose meters, insulin pumps and some newer electronic insulin pens record the timing and amount of basal and bolus insulin doses administered, data which can be easily accessed or downloaded and used to calculate adherence rates [25,30]. Insulin pumps also record entries of carbohydrate intake, however, these data rely on users to manually enter information, and are therefore not objectively measured values.

Patton and colleagues developed the 'BOLUS score,' an adherence assessment algorithm for mealtime insulin administrations via insulin pumps. Adherence rates are calculated by providing one point for each insulin bolus administered during predetermined mealtimes, with a maximum of 3 points/day. In the validation study, certified diabetes educators calculated daily BOLUS scores over the 14 previous days. Using this approach, mealtime insulin adherence demonstrated statistically significant correlations with BGM frequency via meter data and with glycemic control; in fact, the 'BOLUS score' predicted glycemic control more strongly than did BGM frequency [30]. Because this algorithm and the use of insulin pump data to measure adherence are relatively new, data on the utility in other studies or settings are limited. In addition to the timing and frequency of insulin administrations, one of the benefits of using data from insulin pumps is that it can reveal other aspects of nonadherence, such as incorrect insulin administration, delayed boluses and over- or under-dosing insulin.

Considerations & challenges of assessing adherence via device data

Although obtaining adherence data from blood glucose meters is generally feasible and useful, youth may forget to bring any or all of their meters to the clinic appointment, resulting in incomplete estimates of adherence [27]. This is typically less of a problem for insulin pumps, which are connected to the body. Technology glitches such as incorrectly programmed time/date or download failures can cause inaccuracies in downloaded device data. Additionally, the use of these technologies and devices requires an adequate level of health literacy, which may not apply to all individuals and families [25].

The primary benefit of using data from diabetes management technologies for direct, objective measurement is to decrease the potential for recall bias, ensuring greater accuracy [27]. However, the potential for inaccuracies remains. It is typical to review data from the 14 days prior to the clinic appointment, which can result in overestimates of adherence due to 'white coat adherence,' in which individuals follow their regimen more closely just prior to a clinic visit [31]. Similarly, 'reactive adherence' is an increase in adherence due to an awareness of being monitored [32]. Finally, diabetes devices each measure a single diabetes management behavior (i.e., BGM, mealtime insulin administration); while these behaviors are at the core of diabetes management recommendations and are often used as proxies for overall adherence, they do not measure adherence to the complex and multibehavior treatment regimen.

Indirect objective methods

Indirect objective measures of adherence allow investigators to make an 'educated assumption' that a behavior was performed based on other events or observable data that are known to result from or occur in tandem with the target behavior [23,24]. One example of an indirect measure is pharmacy claims data representing the history of filling prescriptions over a particular period of time to determine the rate at which medications are used. For diabetes, such pharmacy claims could include fills of insulin and BGM supplies [23]; however, to our knowledge no studies have used this method for assessing adherence in adolescents with T1D.

Other indirect objective measures of adherence include medication or byproduct levels in body fluids (e.g., blood, urine); however, because oral medications are only infrequently prescribed for this T1D population, this approach is not applicable for most of the behaviors associated with the T1D regimen. One similar biomarker that may be erroneously categorized as an indirect measure of adherence is hemoglobin A1c. Hemoglobin A1c is the key index of overall glycemic control (or, overall diabetes-related health status) and represents the individual's average blood glucose level over the previous 3 months. Hemoglobin A1c is occasionally used as a proxy measure of diabetes adherence in research and practice due to its established relationship with diabetes treatment adherence [6]. However, adherence behaviors account for less than half of the variance in A1c, and this biomarker's value is affected by numerous other influences outside of adherence such as imperfect insulin recommendations, metabolism, puberty, stress, illness, other ingested substances and laboratory errors [6,23]. It is now well documented and agreed upon that hemoglobin A1c is not an appropriate measure of adherence: this biomarker does not provide any conclusive information about an individual or family's execution of particular diabetes management behaviors and is too fraught with other influences to be used to measure or estimate adherence [6,23–24].

• Subjective adherence measures

Subjective measures of diabetes adherence include youth-, parent- and provider-report

questionnaires, structured interviews and logbooks or diaries. Using subjective methods, the reporter rates their impressions or recollections of past or usual adherence behaviors.

Questionnaires

Self-report questionnaires of adherence are typically inventories of specific diabetes management behaviors in which the reporter rates the frequency at which they executed each behavior over a specific period of time. The length, level of detail, recall period and format of the questions and responses may vary depending on the purpose of the questionnaire. For example, one measure may ask "In the past month, how often did you check your blood glucose at least four times per day?", with response options ranging from Never to Almost Always. Another measure may ask, "Over the past 2 weeks, on average how many blood glucose checks did your child complete per day?" with numeric response options. Questionnaires are most appropriately used when there are no feasible objective measures of adherence available, or as a supplement to objective measures [16].

Benefits of questionnaires include that they are often easily accessible (freely available from authors or for a licensing fee from a publisher) and are relatively easy to administer. Respondents can typically complete surveys privately, and youth and families are often very familiar with completing surveys [16]. However, there are limitations in their use with people with low literacy or English proficiency and there is a risk for inaccuracies due to recall bias if a measure's recall period is very long [16]. Individual characteristics may also impact responses. Given the elevated rates of depressive symptoms in adolescents with T1D [33], this may be of particular concern; key features of depression such as memory impairment or inability to concentrate may result in poorer adherence or inaccurate reporting [34]. Responses from individuals with a desire to please or impress the provider/investigator may also be inaccurate due to social desirability bias [23–24,35].

In the following paragraphs, we review several contemporary and frequently used self-report adherence questionnaires.

Self Care Inventory

Development & history

This measure is a 14-item questionnaire originally developed and later revised by La Greca and colleagues [36–38]. The most recent update was validated in 2009 for use with adolescents and parents – the revisions reflect contemporary diabetes management in the post-Diabetes Control and Complications Trial (DCCT) era utilizing intensive insulin regimens [39]. An adapted version is also available for adults with T1D and Type 2 diabetes [40].

Instrument structure

This questionnaire measures the frequency of following provider directions for 14 diabetes care behaviors over 1 month. It encompasses four domains: monitoring and recording glucose, administering and adjusting insulin, regulating meals and exercise, and keeping appointments. Responses are rated on a 5-point Likert scale, ranging from 'never do it' to 'always do this as recommended without fail.' The revised version of the SCI [38] includes an additional question and focuses on specific actions over the last 1–2 months, rather than asking about how often the respondent 'followed recommendations' that were given by the provider. An example question of the SCI-R is, 'how often you check blood glucose with a monitor.' Versions are available for youth- and parent-report.

Time to complete

Approximately 5 min.

Age range

Various versions have been validated from ages 4 to 18 years, and for adults with T1D or Type 2 diabetes [38–42].

Psychometric properties

Studies have shown internal consistency above 0.70 in samples of children, adolescents and adults [38,40–41]. Excellent internal consistency, moderate parent-child agreement and strong test–retest reliability were found among adolescents [39]. Validity has been demonstrated through high correlations with adherence scores as measured by the Diabetes Self-Management Profile (DSMP) [43], described in more detail below.

Considerations

Although this measure was developed before the DCCT trial, the core components of the original and revised version are similar to the current American Diabetes Association guidelines for diabetes management [10–12,39]. The updated measure assesses behaviors related to insulin pump therapy, but is sufficiently general to allow applicability to various pump regimens.

Diabetes Self-Management Profile – Self Report

Development & history

The Diabetes Self-Management Profile – Self Report is a self- or parent-report questionnaire adapted from the DSMP interview (described in detail below) [43] by Wysocki and colleagues [44]. They developed the questionnaire version to eliminate the requirement of trained interviewers for the DSMP interview.

Instrument structure

It is a 24-item scale with separate forms for flexible (basal-bolus or insulin pump) versus conventional (fixed dose) insulin regimens. Items ask about the frequency of adhering to or missing specific diabetes management tasks. Each question has 3–6 response options, not a common Likert scale for the whole measure. For example, "I always took the prescribed amount [of insulin]," or responses ranging from not taking the prescribed amount one to three times to more than ten times [44].

Time to complete

Approximately 5–10 min.

Age range

The measure was validated among youth 8–18 years of age. For youth at least 11 years of age, parents and youths complete their own forms and for youth under 11 years of age the parent complete the questionnaire with the youth present [44].

Psychometric properties

The measure has good internal consistency and parent-youth agreement, and had slightly better psychometric properties than the DSMP interview [44].

Considerations

Parent- and youth-reports are typically scored separately.

Diabetes Self-Management Questionnaire

Development & history

This questionnaire was developed by Markowitz and colleagues [45] to be a very brief tool for adherence assessment to minimize time and resources required for the administration of more in-depth tools such as the DSMP [43].

Instrument structure

The nine-item questionnaire assesses the frequency of diabetes management behaviors in common situations (e.g., adjusting insulin when engaging in an atypical amount of physical activity) over the past month. Response options ranging from 'never' to 'always' and an option to note that the situation is not applicable/relevant [45].

Time to complete

Approximately 10 min.

Age range

This measure was validated for youth 9–15 years of age and their parents.

Psychometric properties

This measure has good construct validity and parent-youth agreement, though parent scores tend to be somewhat higher than youth scores [45]. Internal consistency was relatively low (0.56–0.60) which the authors attributed to the brevity of the measure and minimization of redundancy across items [45]. Validity was demonstrated via strong correlations with other measures of adherence and glycemic control [45].

Considerations

Items are not specific to individual insulin regimens (e.g., pump, injections) but are broadly relevant to both.

Measuring-related constructs

As noted above, the term 'self-management' is related to adherence and encompasses the processes by which individuals and families conduct the recommended tasks of the diabetes regimen [9]. When measuring adherence, investigators are often also interested in understanding self-management processes. Several self-report questionnaires assess self-management processes; one example is the Self-Management of Type 1 Diabetes in Adolescents (SMOD-A) [46]. This 52-item measure includes the following subscales: Collaboration With Parents, Diabetes Care Activities, Diabetes Problem Solving, Diabetes Communication and Goals. This is youth self-report only, with no parallel parent version.

Provider report

Occasionally in studies, healthcare providers may be asked to estimate or rate the adherence of the youth they see as patients via a questionnaire or single-item question. Of course, making educated guesses about patients' adherence often occurs in the course of providing care. However, provider estimates of adherence tend

to be inaccurate, in both directions of over- and underestimates [47–51]. This may be due to provider reliance on health outcomes as a proxy for adherence (which is not accurate/acceptable, as noted above), awareness of previous adherence patterns, miscommunication with the family about their adherence experiences, or provider biases or assumptions based on observable characteristics, such as race/ethnicity, socioeconomic status or age [52,53]. When possible, provider reports should be avoided, interpreted with caution, or used in conjunction with other measures, in both research and clinical settings [24].

Structured interviews

Structured interviews are a method of adherence assessment that takes place via in-person or telephone interview – a trained interviewer asks respondents a series of questions about adherence and scores the responses using a scoring guide. This approach also can allow for follow-up questions regarding barriers and patient perspectives [16]. This approach can include questions on a wide variety of diabetes management behaviors, such as exercise, diet, insulin administration and BGM [16,23]. Structured interviews typically take longer to administer than questionnaires and require trained interviewers to conduct the interview and score responses. Careful training of interviewers is required to prevent eliciting biased responses and ensure accurate scoring and interpretation. Interviewers must be trained to a predetermined level of inter-rater reliability to ensure that questions are being asked and scored precisely according to the structured interview guidelines. Below, we review two structured interviews that assess adherence to the diabetes regimen in adolescents with T1D.

Diabetes Self-Management Profile (DSMP)

Development & History

The DSMP was developed by Harris and colleagues [43] based on an earlier adherence questionnaire and other foundational work on adherence by Hanson and colleagues in the 1980s [54]. It updated the content for contemporary post-DCCT diabetes management and was one of the first structured interviews of adherence for adolescents with T1D.

Instrument structure

The DSMP is administered by a trained interviewer, who asks youth and parents to rate the frequency of conducting 23 diabetes self-management behaviors over the past 3 months across five domains: exercise, hypoglycemia management, diet, blood glucose monitoring and insulin administration and dose adjustment.

Time to complete

Approximately 20–30 min per interview.

Age range

The measure was validated among youth 6–15 years of age. For youth at least 11 years of age, parents and youths complete their own forms; for youth under 11 years of age the parent complete the questionnaire with the youth present [43].

Psychometric properties

Internal consistency for the total score was adequate (0.76), but not for individual domains (<0.50). Parent-youth agreement is moderate. The DSMP has demonstrated validity via correlations with measures of quality of life and glycemic control [43].

Considerations

The DSMP has been used in numerous studies and is often considered a standard by which to validate other adherence measures.

Diabetes 24 h Recall Interview

Development & history

The diabetes 24 h recall interview was first adapted to focus on diabetes behaviors from a dietary recall interview developed in the 1970s [55], and was adapted in the early 1990s [56] and again more recently to reflect current, post-DCCT diabetes management [57].

Instrument structure

The recall interview is a structured interview administered in person or by telephone in which the interviewee is asked to describe all activities over the previous 24 h. The interviewer prompts the interviewee as needed to progress throughout the day and to provide a sufficient level of detail about diabetes-related activities for scoring and analysis, such as food serving sizes or the timing of insulin administrations. The interviews are conducted separately for parents and youth. To obtain an estimate of an average or typical day, interviews are completed on three separate days and averaged [57].

Time to completion

Approximately 20 min per interview.

Age range

Validated with youth aged 6–17 years of age and their parents.

Psychometric properties

Parent–child agreement is acceptable, with highest levels exhibited in the 10–15 year age range [57].

Considerations

The very brief recall period (24 h) may aid recall, however conducting the interview on three occasions can be time intensive and not well-suited for clinical applications. Parent–youth agreement varied by age, with greater reliability in adolescents [57]. From the information gathered in the interview, 13 adherence scores can be calculated in the following diabetes behavior domains: injections (interval, regularity and meal timing), dietary (% of calories from fat and carbohydrates, concentrated sweets, eating frequency), exercise (frequency, duration and type) and BGM (timing, frequency) [57].

Diaries & logbooks

Diary methods include frequent (often daily) personal documentation or reporting of target behaviors [58–60]. Diary reporting can be documented by computer, phone and written forms. The advantages include short recall periods, detailed recording of specific behaviors and the ability to track multiple behaviors as they occur. However, many people may not adhere to the daily logging requirement and it is not uncommon for multiple entries to be made immediately prior to submitting the logbook or diary forms to the investigator or healthcare provider. In addition, record-keeping requires a high level of literacy, which may not be feasible for some individuals and families [23].

A recent advance in diary-based assessment of adherence takes advantage of the growing accessibility to and capabilities of mobile telephones using ecological momentary assessment (EMA) for in-the-moment assessments. Using EMA, individuals provide a sample of behaviors and experiences using a technology device, such as a cell phone within close time proximity to the actual behavior performed with the goal to minimize forgetting or response bias [61]. Mulvaney and colleagues [61] used mobile phones with adolescents with T1D to monitor when BGM and insulin administration events occurred during the day; participants received telephone calls and answered adherence questions via a touch-tone system. Adherence rates for BGM frequency and missed insulin doses measured by EMA were related to self-reported adherence, but not glycemic control. Benefits of EMA for adherence assessment include simplicity of responding and the greatly reduced recall period [61]. Downsides include the opportunity to 'opt out' of responding to prompts and a potential to respond and report positive behaviors only [61]. The authors reported difficulty using EMA with adolescents during school hours due to policies banning mobile phone use at school, however participants often called back after school; while this reduces missing data, it may increase the risk for recall bias [61]. Although this approach has not yet been extensively validated for adherence assessment in adolescents with T1D, this innovative approach heralds an era of using technology to access adolescents in the course of their everyday lives and routine diabetes management behaviors.

Assessment of dietary adherence

Dietary adherence is an important predictor of glycemic control [62]. As Patton [62] notes, suboptimal adherence to providers' recommended dietary guidelines, as measured by adherence to eating behaviors and macronutrient intake, is common in adolescence. There are few recommended diet regimens for adolescents with T1D [63], and wide variation among providers complicates the development of generalizable measures of dietary adherence. Medical nutrition therapy is the most common and best documented guideline in this area; however, its central characteristic is personalization and tailoring [11,63], making it difficult to refer to a core set of common dietary recommendations for adherence assessment purposes.

There are two frequently used measures of dietary adherence in this population: dietary records and 24-h food recalls. Dietary records require individuals to document a complete log of foods and beverages (including serving size, ingredients and other details) consumed over the span of one or more days. The individuals' awareness of being monitored may introduce bias and reduce validity. For example, adolescents may change their behavior to impress the investigator/provider, may omit or modify what is documented, or may restrict food intake to reduce the logging burden. There is also an increased risk of missing data or participant dropout due to the burden of logging,

and the high literacy rates necessary to calculate and record all dietary consumption may reduce generalizability to low-literacy populations [64].

In contrast, 24-h dietary recalls may be conducted at unannounced times, requiring no preceding knowledge from the respondent and possibly reducing behavior changes as a result of being monitored. Similar to the 24-h diabetes recall or diary methods reviewed above, a dietary recall asks individuals to recall and list all foods and beverages consumed in the last 24 h. This may result in less biased reporting over the same 24-h period of time as a daily diary [64]. Potential downsides to this method include inaccuracies in memory and inattention to food intake details, as a high level of details is required about each food and beverage [64]. Furthermore, individual's food intake patterns may change on a daily basis, meaning that a single 24-h recall/record may not accurately reflect eating behavior on other days or in general; to prevent this, multiple measures may be taken across several days and aggregated.

Adherence assessment to inform clinical care

In clinical settings, adherence assessment can be an important gateway to identify when behavior change is needed and intervention is warranted. For example, if an individual has consistently high blood glucose and the provider knows they are following insulin recommendations correctly and consistently, then the provider can feel more confident in deciding to increase the insulin dose. On the other hand, if all of the prescribed insulin is not being consistently administered, then the provider may wish to maintain the current insulin dose and consider whether the treatment approach is the best fit for the patient's lifestyle and situation. In that case, rather than change an insulin ratio, changing the delivery method (e.g., injections vs pump therapy) to better suit the patient's needs may be the more effective treatment decision. Providers may also be interested in the pattern of adherence over time. For example, observing that a particular adolescent is much more adherent in school than on summer vacation allows the provider and family to plan for changes in treatment as needed during periods with less daily structure (e.g., vacation, holidays).

Assessment of adherence can be used not only to inform treatment considerations, but also to identify patients who may need behavioral interventions or social supports to improve adherence and ultimately clinical outcomes. For example, Datye and colleagues [13] offer suggestions on how diabetes care providers might explore common barriers to adherence. Additionally, a decline in adherence may indicate burnout or other psychosocial concerns, in which case a referral for behavioral intervention by a mental health professional may be helpful. Given the numerous and varied behavioral, psychological and interpersonal contributors to suboptimal adherence, interventions to promote adherence often target a range of issues or skills. Indeed, multicomponent interventions that incorporate several types of behavior change strategies have stronger effects on improving glycemic control [65]. Although a comprehensive review of adherence interventions is beyond the scope of this paper, this brief section provides an overview of intervention strategies that have promise for promoting adherence in adolescents with T1D.

Coping skills training involves teaching patients how to better manage or reduce diabetes-related stress and has been shown to increase positive parent–child communication and quality of life [66,67]. To prevent a deterioration in adherence and glycemic control in adolescence, interventions that promote family teamwork and teach problem-solving and communication skills have demonstrated effectiveness in improving family relationships, adherence and glycemic outcomes [68,69]. Additionally, multisystemic therapy and related approaches involve intensive intervention in all settings in which diabetes is managed (e.g., home, school, community settings); such approaches have demonstrated improvements in BGM, glycemic control and number of hospitalizations [70], and may also reduce healthcare costs [71]. In addition to these well-supported interventions, there are also several emerging adherence-promotion interventions that have preliminary support, including provider-delivered interventions such as motivational interviewing [13,72] and delivery of behavioral reminders and feedback via text messaging and other mHealth tools [73–75].

Conclusion

There are many approaches to measure adherence in adolescents with T1D. The most common approaches assess BGM frequency, insulin administration frequency/timing and inventories of numerous specific self-management behaviors. Although objective measures using diabetes management technologies are becoming increasingly accessible in routine diabetes

clinic visits (e.g., meter download data), youth- or parent-report subjective measures are most commonly used. This paper focused on assessing adherence in adolescents with T1D, yet many of these measures and strategies are also relevant and applicable in younger children and in adults, with adaptations for life stage and developmental capacity. The selection of one or more measures should be driven by the research or clinical need – for example, for a diabetes care provider who is concerned about an adolescent's insulin adherence, the most appropriate measurement strategy would emphasize details about insulin administration (e.g., through pump download data) and would include minimal to no detail on adherence to other behaviors that might be included on broader inventory measures (e.g., detailed structured interview of all self-management behaviors). On the other hand, an investigator evaluating a multicomponent intensive behavioral intervention targeting BGM, insulin, dietary intake and clinic attendance adherence might select one or more tools that assess a wide range of behaviors and may not include more granular assessments of any particular behavior.

Future perspective

This review highlights the recent advancements in adherence assessment to keep pace with rapid advances in diabetes management in the post-DCCT era and growing access to sophisticated technologies. Existing measures are frequently revised and updated, and new tools are continually being developed and validated to keep pace with rapid advances in science and technology. As this field continues to progress, it will be important for investigators to agree on a few key adherence measures for common use to allow for comparison of results across studies. Additionally, several strategies for adherence promotion have demonstrated efficacy, but the lasting clinical impact is modest [6]. Future development of interventions may benefit from using validated adherence assessments to individually tailor intervention components to meet the unique patterns and needs of individual youth and families. Moreover, there is potential to integrate feedback to youth and families about their own adherence patterns into routine clinical care; this approach has been used in other pediatric health conditions with impressive improvements in adherence [76,77].

Financial & competing interests disclosure

The work of ME Hilliard and RM Wasserman on this paper was supported by NIH (K12 DK 097696, PI: B Anderson). ME Hilliard is also supported by The Leona M and Harry B Helmsley Charitable Trust. The authors have no other relevant affiliations or financial involvement with any organization or entity with a financial interest in or financial conflict with the subject matter or materials discussed in the manuscript apart from those disclosed.

No writing assistance was utilized in the production of this manuscript.

References

Papers of special note have been highlighted as:
• of interest; •• of considerable interest

1 Miller KM, Foster NC, Beck RW *et al.* Current state of Type 1 diabetes treatment in the U.S.: updated data from the T1D Exchange clinic registry. *Diabetes Care* 38, 971–978 (2015).

2 Rausch JR, Hood KK, Delamater A *et al.* Changes in treatment adherence and glycemic control during the transition to adolescence in Type 1 diabetes. *Diabetes Care.* 35(6), 1219–1224 (2012).

3 Helgeson VS, Honcharuk E, Becker D, Escobar O, Siminerio L. A focus on blood glucose monitoring: relation to glycemic control and determinants of frequency. *Pediatr. Diabetes* 12(1), 25–30 (2011).

4 Nathan DM, DCCT/EDIC Research Group. The Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications study at 30 years: overview. *Diabetes Care.* 37(1), 9–16 (2014).

5 White NH, Sun W, Cleary PA *et al.* Effect of prior intensive therapy in Type 1 diabetes on 10-year progression of retinopathy in the DCCT/EDIC: comparison of adults and adolescents. *Diabetes* 59(5), 1244–1253 (2010).

6 Hood KK, Peterson CM, Rohan JM, Drotar D. Association between adherence and glycemic control in pediatric Type 1 diabetes: a meta-analysis. *Pediatrics* 124(6), e1171–e1179 (2009).

7 Patton SR. Adherence to glycemic monitoring in diabetes. *J. Diabetes. Sci. Technol.* 9(3), 668–675 (2015).

8 Ziegler R, Heidtmann B, Hilgard D, Hofer S, Rosenbauer J, Holl R. Frequency of SMBG correlates with HbA1c and acute complications in children and adolescents with Type 1 diabetes. *Pediatr. Diabetes.* 12, 11–17 (2011).

9 Modi AC, Pai AL, Hommel KA *et al.* Pediatric self-management: a framework for research, practice, and policy. *Pediatrics* 129(2), e473–e485 (2012).

10 American Diabetes Association. Children and adolescents. Sec 11. In standards of medical care in diabetes – 2015. *Diabetes Care* 38(Suppl. 1), S70–S76 (2015).

11 American Diabetes Association. Foundations of care: Education, nutrition, physical activity, smoking cessation, psychosocial care, and immunization. Sec 4. In standards of medical care in diabetes – 2015. *Diabetes Care* 38(Suppl. 1), S20–S30 (2015).

12 American Diabetes Association. Glycemic targets. Sec 6. In standards of medical care in diabetes – 2015. *Diabetes Care* 38(Suppl. 1), S33–S40 (2015).

13 Datye KA, Moore DJ, Russell WE, Jaser SS. A review of adolescent adherence in Type 1 diabetes and the untapped potential of diabetes providers to improve outcomes. *Curr. Diab. Rep.* 15(8), 621 (2015).

- **This contemporary review provides a comprehensive overview of the important role healthcare providers can play in routinely assessing and promoting adherence in their adolescent patients with T1D.**

14 Aronson JK. Compliance, concordance, adherence. *Br. J. Clin. Pharmacol.* 63(4), 383–384 (2007).

15 Quick V, Lipsky LM, Laffel LM, Mehta SN, Quinn H, Nansel TR. Relationships of neophobia and pickiness with dietary variety, dietary quality and diabetes management adherence in youth with Type 1 diabetes. *Eur. J. Clin. Nutr.* 68(1), 131–136 (2014).

16 Quittner AL, Modi AC, Lemanek KL, Ievers-Landis CE, Rapoff MA. Evidence-based assessment of adherence to medical treatments in pediatric psychology. *J. Pediatr. Psychol.* 33(9), 916–936 (2008).

- **This instructive paper reviews adherence measures from a range of pediatric chronic health conditions, including T1D, and provides guidance for common practices in adherence assessment across populations.**

17 Karlsson A, Arman M, Wikblad K. Teenagers with Type 1 diabetes – a phenomenological study of the transition towards autonomy in self-management. *Int. J. Nurs. Stud.* 45(4), 562–570 (2008).

18 Duke DC, Harris MA. Executive function, adherence, and glycemic control in adolescents with Type 1 diabetes: a literature review. *Curr. Diab. Rep.* 14(10), 532 (2014).

19 Iskander JM, Rohan JM, Shroff Pendley J, Delamater A, Drotar D. A 3-year prospective study of parent-child communication in early adolescents with Type 1 diabetes: relationship to adherence and glycemic control. *J. Pediatr. Psychol.* 40, 109–120 (2015).

20 Hilliard ME, Holmes CS, Chen R, Maher K, Robinson E, Streisand R. Disentangling the roles of parental monitoring and family conflict in adolescents' management of Type 1 diabetes. *Health Psychol.* 32, 388–396 (2013).

21 Markowitz JT, Garvey KC, Laffel LM. Developmental changes in the roles of patients and families in Type 1 diabetes. *Curr. Diabetes Rev.* 11(4), 231–238 (2015).

22 Wiebe DJ, Chow CM, Palmer DL *et al.* Developmental processes associated with longitudinal declines in parental responsibility and adherence to Type 1 diabetes management across adolescence. *J. Pediatr. Psychol.* 39(5), 532–541 (2014).

23 Gonzalez JS, Schneider HE. Methodological issues in the assessment of diabetes treatment adherence. *Curr. Diab. Rep.* 11(6), 472–479 (2011).

- **Gonzalez and colleagues offer a thoughtful review of adherence assessment strategies for diabetes. While their paper focuses primarily on issues relevant to adherence to Type 2 diabetes management recommendations in adults, many overlapping issues and approaches are relevant to adolescents with T1D.**

24 Hilliard ME. Principles of health behavior measurement. In: *The Handbook of Health Behavior Change*. Riekert K, Ockene JK, Pbert L (Eds). Springer Publishing Company, New York, NY, USA, 465–481 (2013).

25 Driscoll KA, Young-Hyman D. Use of technology when assessing adherence to diabetes self-management behaviors. *Curr. Diab. Rep.* 14(9), 521 (2014).

- **Given rapid advances in diabetes management technologies, Driscoll and Young-Hyman's review of how to use technologies for adherence assessment is timely and instructive for contemporary clinical care and research focusing on adherence.**

26 Kichler JC, Kaugars AS, Maglio K, Alemzadeh R. Exploratory analysis of the relationships among different methods of assessing adherence and glycemic control in youth with Type 1 diabetes mellitus. *Health Psychol.* 31(1), 35–42 (2012).

- **This study's head-to-head comparison of different adherence assessment strategies provides useful insights into the relative benefits and downsides of different instruments and approaches.**

27 Guilfoyle SM, Crimmins NA, Hood KK. Blood glucose monitoring and glycemic control in adolescents with Type 1 diabetes: meter downloads versus self-report. *Pediatr. Diabetes.* 12(6), 560–566 (2011).

28 Miller KM, Beck RW, Bergenstal RM *et al.* Evidence of a strong association between frequency of self-monitoring of blood glucose and hemoglobin a1c levels in T1D Exchange Clinic Registry participants. *Diabetes Care* 36(7), 2009–2014 (2013).

29 Phillip M, Danne T, Shalitin S *et al.* Use of continuous glucose monitoring in children and adolescents (*). *Pediatr. Diabetes* 13(3), 215–228 (2012).

30 Patton SR, Clements MA, Fridlington A, Cohoon C, Turpin AL, Delurgio SA. Frequency of mealtime insulin bolus as a proxy measure of adherence for children and youths with Type 1 diabetes mellitus. *Diabetes Technol. Ther.* 15(2), 124–128 (2013).

31 Driscoll KA, Johnson SB, Tang Y, Yang F, Deeb LC, Silverstein JH. Does blood glucose monitoring increase prior to clinic visits in children with Type 1 diabetes? *Diabetes Care* 34(10), 2170–2173 (2011).

32 Sutton S, Kinmonth AL, Hardeman W *et al.* Does electronic monitoring influence adherence to medication? Randomized controlled trial of measurement reactivity. *Ann. Behav. Med.* 48(3), 293–299 (2014).

33 Hood KK, Beavers DP, Yi-Frazier J *et al.* Psychosocial burden and glycemic control during the first 6 years of diabetes: results from the SEARCH for Diabetes in Youth study. *J. Adolesc. Health* 55(4), 498–504 (2014).

34 McGrady ME, Laffel L, Drotar D, Repaske D, Hood KK. Depressive symptoms and glycemic control in adolescents with Type 1 diabetes: mediational role of blood glucose monitoring. *Diabetes Care* 32(5), 804–806 (2009).

35 Wagner G, Miller LG. Is the influence of social desirability on patients' self-reported adherence overrated? *J. Acquir. Immune Defic. Syndr.* 35(2), 203–204 (2004).

36 La Greca AM, Swales T, Klemp S, Madigan S. Self-care behaviors among adolescents with diabetes. Presented at: *9th Annual Convention of the Society for Behavioral Medicine*. Seattle, WA, USA (1988).

37 La Greca AM. *Brief Manual for the Self Care Inventory.* Miami, FL, USA (1992).

38 La Greca AM. *Manual for the Self Care Inventory.* Miami, FL, USA (2004).

39 Lewin AB, LaGreca AM, Geffken GR *et al.* Validity and reliability of an adolescent and parent rating scale of Type 1 diabetes adherence behaviors: the Self-Care Inventory (SCI). *J. Pediatr. Psychol.* 34(9), 999–1007 (2009).

40 Weinger K, Butler HA, Welch GW, La Greca AM. Measuring diabetes self-care: a psychometric analysis of the Self-Care Inventory-Revised with adults. *Diabetes Care* 28(6), 1346–1352 (2005).

41 Davis CL, Delamater AM, Shaw KH *et al.* Parenting styles, regimen adherence, and glycemic control in 4- to 10-year-old children with diabetes. *J. Pediatr. Psychol.* 26(2), 123–129 (2001).

42 Wysocki T, Taylor A, Hough BS, Linscheid TR, Yeates KO, Naglieri JA. Deviation from developmentally appropriate self-care autonomy. Association with diabetes outcomes. *Diabetes Care* 19(2), 119–125 (1996).

43 Harris MA, Wysocki T, Sadler M *et al.* Validation of a structured interview for the assessment of diabetes self-management. *Diabetes Care* 23(9), 1301–1304 (2000).

44 Wysocki T, Buckloh LM, Antal H, Lochrie A, Taylor A. Validation of a self-report version of the diabetes self-management profile. *Pediatr. Diabetes* 13(5), 438–443 (2012).

45 Markowitz JT, Laffel LM, Volkening LK *et al.* Validation of an abbreviated adherence measure for young people with Type 1 diabetes. *Diabet. Med.* 28(9), 1113–1117 (2011).

46 Schilling LS, Dixon JK, Knafl KA *et al.* A new self-report measure of self-management of Type 1 diabetes for adolescents. *Nurs. Res.* 58(4), 228–236 (2009).

47 Copher R, Buzinec P, Zarotsky V, Kazis L, Iqbal SU, Macarios D. Physician perception of patient adherence compared with patient adherence of osteoporosis medications from pharmacy claims. *Curr. Med. Res. Opin.* 26(4), 777–785 (2010).

48 Miller LG, Liu H, Hays RD *et al.* How well do clinicians estimate patients' adherence to combination antiretroviral therapy? *J. Gen. Intern. Med.* 17(1), 1–11 (2002).

49 Daniels T, Goodacre L, Sutton C, Pollard K, Conway S, Peckham D. Accurate assessment of adherence: self-report and clinician report vs electronic monitoring of nebulizers. *Chest* 140(2), 425–432 (2011).

50 Murri R, Ammassari A, Trotta MP *et al.* Patient-reported and physician-estimated adherence to HAART: social and clinic center-related factors are associated with discordance. *J. Gen. Intern. Med.* 19(11), 1104–1110 (2004).

51 Shemesh E, Shneider BL, Savitzky JK *et al.* Medication adherence in pediatric and adolescent liver transplant recipients. *Pediatrics* 113(4), 825–832 (2004).

52 Lutfey KE, Ketcham JD. Patient and provider assessments of adherence and the sources of disparities: evidence from diabetes care. *Health Serv. Res.* 40, 1803–1817 (2005).

53 Murri R, Antinori A, Ammassari A *et al.* Physician estimates of adherence and the patient-physician relationship as a setting to improve adherence to antiretroviral therapy. *J. Acquir. Immune Defic. Syndr.* 31, S158–S162 (2002).

54 Hanson CL, Henggeler SW, Burghen GA. Social competence and parental support as mediators of the link between stress and metabolic control in adolescents with insulin-dependent diabetes mellitus. *J. Consult. Clin. Psychol.* 55(4), 529–533 (1987).

55 Marquis KH, Ware JE. *Measures of Diabetic Patient Knowledge, Attitudes and Behavior Regarding Self-Care: Summary Report.* Rand Corporation, Santa Monica, CA, USA (1979).

56 Freund A, Johnson SB, Silverstein J, Thomas J. Assessing daily management of childhood diabetes using 24-hour recall interviews: reliability and stability. *Health Psychol.* 10(3), 200–208 (1991).

57 Holmes CS, Chen R, Streisand R *et al.* Predictors of youth diabetes care behaviors and metabolic control: a structural equation modeling approach. *J. Pediatr. Psychol.* 31(8), 770–784 (2006).

58 Modi AC, Lim CS, Yu N, Geller D, Wagner MH, Quittner AL. A multi-method assessment of treatment adherence for children with cystic fibrosis. *J. Cyst. Fibros.* 5(3), 177–185 (2006).

59 Modi AC, Quittner AL. Utilizing computerized phone diary procedures to assess health behaviors in family and social contexts. *Child Health Care* 35, 29–45 (2006).

60 Wiener L, Riekert K, Ryder C, Wood LV. Assessing medication adherence in adolescents with HIV when electronic monitoring is not feasible. *AIDS Patient Care STDS* 18(9), 527–538 (2004).

61 Mulvaney SA, Rothman RL, Dietrich MS *et al.* Using mobile phones to measure adolescent diabetes adherence. *Health Psychol.* 31(1), 43–50 (2012).

62 Patton SR. Adherence to diet in youth with Type 1 diabetes. *J. Am. Diet. Assoc.* 111(4), 550–555 (2011).

- **This well-written review addresses adherence to nutrition guidelines, an important and relatively less well-documented topic than adherence to other components of T1D regimens.**

63 Horan KL, O'Sullivan-Maillet JK, Wien MA, Touger-Decker RE, Matheson PB, Byham-Gray LD. An overview of nutrition and diabetes management. *Top. Clin. Nutr.* 21(4), 328–340 (2006).

64 Thompson FE, Subar AF, Loria CM, Reedy JL, Baranowski T. Need for technological innovation in dietary assessment. *J. Am. Diet. Assoc.* 110(1), 48–51 (2010).

65 Hood KK, Peterson CM, Rohan JM, Drotar D. Interventions with adherence-promoting components in pediatric Type 1 diabetes. *Diabetes Care* 33(7), 1658–1664 (2010).

- **This meta-analysis synthesizes a large body of literature and offers useful insights and recommendations for adherence-promotion interventions for youth with T1D.**

66 Grey M, Boland EA, Davidson M, Li J, Tamborlane WV. Coping skills training for youth with diabetes mellitus has long-lasting effects on metabolic control and quality of life. *J. Pediatr.* 137, 107–113 (2000).

67 Grey M, Whittemore R, Jaser S *et al.* Effects of coping skills training in school-age children with Type 1 diabetes. *Res. Nurs. Health* 32(4), 405–418 (2009).

68 Laffel LM, Vangsness L, Connell A, Goebel-Fabbri A, Butler D, Anderson B. Impact of ambulatory, family-focused teamwork intervention on glycemic control in youth with Type 1 diabetes. *J. Pediatr.* 142(4), 409–416 (2003).

69 Wysocki T, Harris MA, Buckloh LM *et al.* Randomized, controlled trial of behavioral family systems therapy for diabetes: maintenance and generalization of effects on parent-adolescent communication. *Behav. Ther.* 39, 33–46 (2008).

70 Ellis DA, Frey MA, Naar-King S, Templin T, Cunningham P, Cakan N. Use of multisystemic therapy to improve regimen adherence among adolescents with Type 1 diabetes in chronic poor metabolic control. *Diabetes Care.* 28, 1604–1610 (2005).

71 Harris MA, Wagner DV, Heywood M, Hoehn D, Bahia H, Spiro K. Youth repeatedly hospitalized for DKA: proof of concept for novel interventions in children's healthcare (NICH). *Diabetes Care* 37, e125–e126 (2014).

72 Powell PW, Hilliard ME, Andrson BJ. Motivational interviewing to promote adherence behaviors in pediatric Type 1 diabetes. *Curr. Diab. Rep.* 14(531), 1–8 (2014).

73 Markowitz JT, Harrington KR, Laffel LMB. Technology to optimize pediatric diabetes management and outcomes. *Curr. Diab. Rep.* 13, 877–885 (2013).

74 Herbert L, Owen V, Pascarella L, Streisand R. Text message interventions for childrens and adolescents with Type 1 diabetes: a systematic review. *Diabetes Technol. Ther.* 15(5), 1–9 (2013).

75 Cafazzo JA, Casselman M, Hamming N, Katzman DK, Palmert MR. Design of an mHealth app for the self-management of adolescent Type 1 diabetes: a pilot study. *J. Med. Internet Res.* 14(3), 1–19 (2012).

76 Herzer M, Ramey C, Rohan J, Cortina S. Incorporating electronic monitoring feedback into clinical care: a novel and promising adherence promotion approach. *Clin. Child Psychol. Psychiatry.* 17, 505–518 (2012).

77 Rohan JM, Drotar D, Perry AR, McDowell K, Malkin J, Kercsmar C. Training health care providers to conduct adherence promotion in pediatric settings: an example with pediatric asthma. *Clin. Pract. Pediatr. Psychol.* 1, 314–325 (2013).