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Assessment of Diabetes Regimen Disease Care in Youth with Type 1 Diabetes via the Diabetes Behavior Rating Scale and the 24-Hour Diabetes Interview

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ASSESSMENT OF DIABETES REGIMEN DISEASE CARE IN YOUTH WITH TYPE 1 DIABETES VIA THE DIABETES BEHAVIOR RATING SCALE AND THE 24-HOUR DIABETES INTERVIEW

A thesis submitted in partial fulfillment of the requirements for the degree of Master of Science at Virginia Commonwealth University

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The psychometric properties of two measures of diabetes disease care, the Diabetes Behavior Rating Scale (DBRS) and the 24-hr Diabetes Interview (24-hr) were evaluated. The 24-hr is a widely used, structured interview while the DBRS is a self-administered, fixed-choice questionnaire. Both measures were administered to 250 youth with Type 1 Diabetes (aged 11–14 years) and their parents. Overall, both measures demonstrate adequate psychometric properties. The DBRS and the 24-hr demonstrated good incremental validity and low convergent validity with each adding significant additive value. Both measures demonstrated good concurrent validity with HbA1c. As expected, scores on the 24-hr demonstrated less than adequate test-retest reliability and both measures demonstrated low parent/youth agreement. Interestingly, external validity analyses demonstrated DBRS scores were moderately related to HbA1c in non-pump but not pump regimens, while the 24-hr displayed acceptable external validity. Only three subscales significantly contributed to HbA1c suggesting a more parsimonious assessment measure. This novel, brief combination could prove efficacious for clinical practice.

Assessment of Diabetes Regimen Disease Care in Youth with Type 1 Diabetes via the Diabetes Behavior Rating Scale and the 24-Hour Diabetes Interview

Type 1 Diabetes (T1D) is the most common chronic medical condition of childhood and adolescence and affects 1 in 400-600 youth (American Diabetes Association [ADA], 2009). Successful diabetes management requires a complex interweaving of daily disease care behaviors of insulin administration, blood glucose monitoring, diet and exercise to achieve good metabolic control. Disease care measures are influenced by sociodemographic factors which potentially can influence the psychometric properties of a measure. The transition from childhood to adolescence produces changes in degree of child responsibility for disease care and the rate of parent/youth agreement, both of which bear directly on the validity of a measure. Reliability and validity are important psychometric properties to examine for each disease care measure. Comprehensive measurement of these behaviors is approached via a variety of techniques. Some assessment measures are comprised of specific indices of behavior, e.g., frequency of blood glucose monitoring, while others sample a broader metacognitive understanding of disease care processes, e.g., knowledge of when to make modifications in the regimen. The proposed study will review two measures of diabetes disease care which have different administration formats, content, and assess different temporal intervals to compare their basic psychometric properties. After evaluation of their reliability and validity individually, the disease care measures will be combined to determine if together they provide a complementary, more comprehensive description of disease care management. Lastly, this study will uniquely examine the sociodemographic factors of youth age and level of disease care responsibility to determine if either influences the validity of each measure.

Type 1 Diabetes

Type 1 Diabetes (T1D) is a complex chronic illness which requires continuous medical care, youth and parent disease management behaviors, and education to prevent acute adverse events and reduce the risk of long-term complications (ADA, 2009). In T1D the immune system mistakes insulin for a foreign substance and systematically and slowly destroys the beta cells which produce it. Upon beta cell destruction, the body cannot produce insulin, a hormone necessary to allow glucose to permeate the cellular membrane and provide fuel to organs. Unabsorbed glucose remains concentrated in the blood and produces hyperglycemia, or high blood glucose levels, which can lead to diabetic coma if untreated. Exogenous insulin is necessary to maintain adequate glucose uptake and blood glucose levels must be carefully monitored. In addition, hypoglycemia, or low blood glucose levels may also occur as a consequence of the exogenous insulin. The dangers of both hyperglycemia and hypoglycemia create a constant balancing act. Youth with T1D face multiple challenges if proper disease care is not executed well. Chronic complications secondary to sustained hyperglycemia include retinopathy, nephropathy, cardiovascular disease, gum disease, and limb amputation (ADA, 2009). Acute complications from hypoglycemia, include dizziness, headaches, sweating, diminished attention, and if untreated, seizures or coma (ADA, 2009).

Metabolic Control

Excess glucose binds immediately and irreversibly to available hemoglobin in a process called glycosylation. Glycosylated hemoglobin (HbA1c) is an index of the percentage of bound or glycosylated hemoglobin molecules. HbA1c is superior to a single blood glucose reading as an indicator of chronic metabolic control because it is a composite index over the previous two- to three-month period, the lifespan of a hemoglobin molecule. Individuals without T1D have

HbA1c levels which range from 4.6-6% and correspond to average blood concentrations of 80-120 milligrams/deciliter (ADA, 2009). The HbA1c goal for school-age children with T1D ages 8-12 is < 8% and for adolescents and young adults ages 13-19 is < 7.5% (ADA, 2009). Lower HbA1c levels are recommended for adolescents due to the lower risk of hypoglycemic complications in puberty and higher risk of hyperglycemia (ADA, 2009). The Diabetes Control and Complications trial found the risk of long-term disease complications decreases with as little as one percent decrease in HbA1c, which stresses the importance of lowering HbA1c levels (1994). HbA1c is widely accepted as a useful index for mean blood glucose levels and is widely used as a marker of successful control of diabetes.

Predictors of Disease Care

Adherence to multiple recommendations of disease care is necessary to achieve successful metabolic control. Appropriate disease care behaviors generally are associated with better metabolic control and reduce long-term complications (Diabetes Control and Complications Trial [DCCT], 1993), but adherence to a fairly complicated medical regimen is necessary (Morris et al., 1997). Even with proper disease care, reports of disease care behaviors explain significant but not all variance in HbA1c. Adherence to disease care behaviors for youth with chronic conditions is generally below 50% and is considered the single, greatest cause of poorer health outcomes (Quittner, Espelage, levers-Landis, & Drotar, 2000). Previous research suggests diabetes disease care is not a monolithic concept because adolescents may better manage some regimen aspects than others (Stewart, Emslie, Klein, Haus & White, 2005). For example, in a study which examined the 24-hour Diabetes interview, the mean correlation between the six adherence factors was .06, which supports a multivariate versus univariate conceptualization of compliance (Johnson, Freund, Silverstein & Hanson, 1990). Important

disease care behaviors include but are not limited to: Insulin injections, basal/bolus, or continuous subcutaneous insulin infusion (CSII) through an insulin pump, frequent blood glucose monitoring, attention to diet and meal frequency, and regular exercise. In addition, other factors related to metabolic control are also important to consider for a more comprehensive understanding of disease care.

The relation between disease care behaviors and HbA1c will be examined to determine the relative importance of each. The following disease care behaviors are several of the most frequently cited in the literature and establish a guideline of important factors which contribute to disease care. This will allow for a basis of comparison when specific disease care measures are examined in greater depth.

Insulin Administration.

Overview. Youth with diabetes do not produce insulin and insulin therapy is necessary to survive. Insulin regimens are highly variable and individualized based on physician recommendations and youth metabolic control to obtain the best glycemic target (Crasto, Jarvis & Khunti, 2009). One of the primary aims of insulin therapy is to teach youth to adjust insulin based on blood glucose levels and match carbohydrate counts or dietary exchanges (Crasto et al., 2009). The most common types of insulin administration include continuous subcutaneous insulin infusion (CSII), basal/bolus regimens, and multiple daily injections (MDI).

Insulin regimen. Youth with T1D typically follow three types of insulin regimens. Continuous Subcutaneous Insulin Infusion (CSII) occurs via an insulin pump and can reduce the progression of long-term complications (DCCT, 1993). Insulin doses are delivered through a catheter placed under the skin. A basal rate is delivered continuously over 24-hours to keep blood glucose levels in range between meals and overnight. Bolus doses of insulin are manually

administered to cover carbohydrates in meals and to correct or supplement basal doses. Alternatively, basal bolus regimens offer more of a physiological replacement of insulin and provide flexibility for variable lifestyles without the use of a pump (Crasto et al., 2009). In basal bolus regimens, short-acting insulin (regular insulin or short-acting insulin analogues) is used for each meal, and long-acting basal insulin (NPH, glargine or detemir) provides background insulin to cover fasting and preprandial glucose concentrations (Crasto et al., 2009). Insulin doses can be adjusted in response to blood glucose patterns, carbohydrate intake, anticipated activity and stress. This regimen requires frequent blood glucose monitoring and insulin titration (Crasto et al., 2009). Multiple Daily Injections include two or three daily injections of short-acting and intermediate-acting insulin and may involve mixing of the two (Crasto et al., 2009). Insulin dose and timing are adjusted according to blood glucose concentrations, meal times or other factors. The timing of meals and exercise are relatively rigid, with minimal room for flexibility, and nocturnal hypoglycemia is problematic. This regimen may involve snacking between meals to prevent hypoglycemia (Crasto et al., 2009).

Recommendations. The DCCT (1993) recommends intensive insulin therapy (three or more injections per day) or CSII to obtain optimal HbA1c and to reduce long-term disease complications. Multiple factors influence the choice of insulin regimen and include age considerations, quality of life, and cost effectiveness. For example, the cost of CSII pumps might limit their use. Alternatively, younger youth might not be able to appropriately handle the nuances of CSII therapy. While some youth might choose CSII for greater quality of life with more flexible regimens, other families might transfer from CSII to basal bolus regimens because of inappropriate insulin pump use.

Relation with HbA1c. Insulin regimen is one of the strongest predictors of metabolic control (DCCT, 1993). Stewart et al. (2005) found the single most important predictor of HbA1c was adolescents' adjustment to their insulin to keep blood glucose levels normal. Meta-analyses of studies on CSII therapy have revealed a cumulative reduction of 20.5% to 20.9% in HbA1c when compared with multiple daily injection (MDI) therapy (Pickup, Mattock, & Kerry, 2002; Weissberg-Benchell, Antisdel-Lomaglio & Seshardi, 2003). In a cohort that switched from MDI to CSII, a significant decrease in HbA1c was demonstrated after the start of CSII (Nimri et al., 2006). Positive results have been reported with an intensive twice-daily injection approach with a rigid meal schedule. However, this more inflexible approach may not fit with every lifestyle (Dorchy, 2003; Hvidore Study Group on Childhood Diabetes, 2005; Soliman, Omar, Rizk, Awwa & AlGhobashy, 2006).

Measurement considerations. Because of insulin's importance to the diabetes regimen, disease care measures typically contain some query of adherence to insulin regimen. One aspect to consider in the measurement of insulin administration is the type of insulin regimen. Insulin doses are highly variable, even within the same regimen type. Measures frequently assess adherence to insulin in a broader sense and do not have tailored questions based on insulin regimen type and dosage. It is also common for youth to change insulin regimens or doses at every endocrinology appointment which leads to errors when multiple measurement points are assessed. Informant confusion of question meaning might also impact measurement. Although many measures specify insulin type, many youth and parents are unsure of the difference between basal/bolus regimens and multiple daily injections and often confuse the two. In sum, although insulin use is a critical factor in understanding metabolic control, it is highly variable, and this variance is frequently not taken into account in disease care measures.

Blood Glucose Monitoring

Overview. Frequent blood glucose monitoring is necessary to ensure the proper balance of insulin, exercise and meals. Typically, a finger prick derives a drop of blood which is placed on a test strip and read by a blood glucose meter. The American Diabetes Association (ADA, 2009) recommends youth check blood glucose levels a minimum of four times daily. Current recommendations for blood glucose levels in the near normal range are between 80-120 mg/dl. (ADA, 2009). If blood glucose levels are out of range, corrective actions must be taken such as administration of insulin injection/bolus or appropriate diet modification (ADA, 2009).

Relation with HbA1c. More frequent blood glucose monitoring is consistently associated with better HbA1c (Hanson et al., 1996; Johnson et al., 1992; Swift, Chen, Hershberger, & Holmes, 2006). After controlling for gender, duration of diabetes, and Tanner stage, adherence to blood glucose monitoring recommendations remained the consistent, significant predictor of glycemic control (Anderson, Ho, Brackett, Finkelstein and Laffel, 1997). Further, glycemic control improved significantly as the frequency of blood glucose monitoring increased.

Measurement considerations. Although blood glucose monitoring displays a strong association with HbA1c, measurement of this concept varies. Blood glucose monitoring is commonly measured by a simple frequency count, with queries surrounding whether youth check during an activity or before or after meals. Alternatively, determination of how frequently blood glucose levels are kept in range can be assessed. It is difficult to obtain accurate estimations of blood glucose monitoring in disease care measures. For example, parents might be unaware of youth's actual blood glucose numbers and frequency of checks or youth might forget exact blood glucose levels. For this reason, numerous studies bypass or supplement self-report

data with electronic data from blood glucose meters (Burdick et al., 2004; Lafell et al., 2007; Nansel et al., 2009).

Nutrition

Overview. The American Diabetes Association (2009) nutrition recommendations suggest youth with T1D adjust insulin doses to meal content, meal size, and activity levels to achieve good metabolic control. Based on insulin regimen recommendations, youth might count their carbohydrates and vary insulin amounts on carbohydrates ingested. Typically, 1 unit of short-acting insulin is calculated for each 15 grams of carbohydrate. To keep blood glucose on target, youth might also ingest extra carbohydrates or glucose tablets to increase low blood glucose levels. Nutritional intake is associated with fluctuations in blood glucose levels and insulin doses are adjusted based on the amount/type of food/drink ingested and blood glucose levels. Based on recommendations of the Food and Drug Administration (FDA) for healthy youth, ideal frequency of food consumption is six meals or snacks daily, with a greater percentage of calories from carbohydrates (60%) than fats (25-35%; Trumbo, Schlicker, Yates, & Poos, 2002).

Relation with HbA1c. The DCCT indicates patients who follow their physician-recommended diet 90% or more of the time have a 1% lower HbA1c than those that are less adherent (Delahanty & Halford, 1993). Specific dietary composition, including diet consistency and adjustments of insulin dose for variations in food intake, are associated with lower HbA1c (Delahanty et al., 1993). Delahanty and colleagues (2009) found higher insulin doses, lower carbohydrate intake, and higher monounsaturated, saturated, and total fat intake were associated with higher HbA1c, indicative of poorer metabolic control. However, research with nutrition and HbA1c remains inconsistent. It is unclear if a particular dietary macronutrient composition

promotes improved HbA1c (Garg, Bantle & Henry, 1994; Gerhard et al., 2004; Komiyama, Kaneko & Sato, 2002; Neilsen, Jonsson & Iverson, 2005).

Measurement considerations. Nutrition is not a monolithic concept and depends on insulin regimen, age, gender, and sociodemographic considerations. Many clinics offer the option for youth to meet with a nutritionist, which allows for greater knowledge of nutrition recommendations. Regimen type is also vital to consider when nutrient requirements are assessed. Youth on multiple daily injections might be less flexible in their nutrient requirements, while youth on CSII or MDI have greater flexibility.

Exercise

Overview. Although the majority of guidelines are not supported by evidence-based findings due to lack of research, regular physical activity has been shown to be beneficial to body composition, blood pressure, insulin sensitivity, blood glucose utilization, blood lipid profiles, and positively affect quality of life and social interaction (Laaksonen, Atalay & Niskanen, 2000; Norris, Carrol & Cochrane, 1990; Wasserman & Zinman, 1994). The American Diabetes Association (2009) suggests all levels of physical activity can be performed in individuals without disease complications who are in good blood glucose control. Since exercise burns glucose, blood glucose levels should be checked prior to and after exercise, and snacks made available to prevent hypoglycemia, as needed. The ADA and American College of Sports Medicine recommends blood sugar levels above 100 mg/dl and below 250 mg/dl- 300mg/dl and delaying exercise when blood sugars are above 300 mg/dl (Vanelli, 2006). Suggested levels can be achieved by close monitoring of blood glucose levels with recommendations to check 90 minutes before an activity. If blood glucose levels are elevated, exercise is one way to lower

glucose levels. The American Academy of Sports Medicine recommends a minimum of 30-60 minutes of moderate physical activity daily (Silverstein et al., 2005).

Relation with HbA1c. While exercise may be beneficial to various health outcomes, the relation between exercise and metabolic control is controversial (Austin, Warty, Janosky, & Arslanian, 1993; Hanson et al., 1996; Silverstein et al., 2005; Stewart, Emslie, Klein, Haus, & White, 2005; Wasserman & Zinman, 1994). For example, in a lower SES sample of Puerto Rican youth, lower HbA1c levels were associated with more frequent exercise (Streisand, Swift, Wickmark, Chen and Holmes, 2002). In contrast, Hanson et al. (1996) and Stewart et al. (2005) found no significant relation between exercise and HbA1c levels. However, most research shows positive aspects of exercise on overall health, which must be taken into consideration as an important aspect of not only disease care, but general health and well-being.

Measurement considerations. Although exercise shows a weaker relation with HBA1c compared to other disease care behaviors, it is a positive factor in good disease care outcomes. Despite the positive benefits, it is not uncommon for parents, schools, staff, or physicians to discourage rigorous physical activity out of fear of severe hypoglycemia. In addition, monitoring blood glucose is especially important for youth who play sports. Snacks or glucose tablets should be made available if blood glucose levels are low. Barriers to measurement of exercise also are important to consider. For example, when youth play outdoors with friends or participate in sports, it is difficult to accurately gauge the level of exertion.

Other Factors Associated with HbA1c

Although the previous four disease care factors are most frequently associated with HbA1c, other factors have also been shown to impact metabolic control. Psychological distress, in particular depression, is linked to poorer metabolic control in adolescents (Grey, 2002;

Hegelson, Reynolds, Siminerio, Escobar & Becker, 2009). Youth living with married biological parents, better parental employment status, and less conflicted familial relationships generally relate to better HbA1c (Cameron et al., 2008; Swift, Chen, Hershberger & Holmes, 2006). Eating disturbances are also linked to poorer HbA1c (Hegelson et al., 2009; Rubin & Peyrot, 2001). Although these factors will not be discussed in depth, they are important potential contributing factors to better understand the complex nature of the disease, and how difficult, or even unattainable perfect disease care adherence is, particularly with factors beyond youth's control.

Adolescence and Disease Care Measurement.

The complicated regimen of diabetes disease care behaviors often is particularly challenging in adolescence (Anderson & Brackett, 2005). The transition into adolescence is frequently marked by declines in disease care behaviors, metabolic control, and psychosocial well-being (Anderson, Ho, Brackett, Finkelstein, & Laffel, 1997; Jacobson et al., 1990; Wysocki, 1993; Wysocki et al., 1996). On average, adolescents exhibit poorer metabolic control than either younger youth or adults (Anderson et al., 1997).

Puberty. Pubertal hormones can contribute to poorer metabolic control (Rogers, 1992). During puberty, rapid hormonal and metabolic changes occur. The profound metabolic changes caused by T1D may disrupt the usual progressions of hormonal and metabolic changes seen during puberty (Rogers, 1992). In addition, the metabolic changes seen during puberty might destabilize glycemic control and impact complications (Rogers, 1992). Insulin resistance occurs during puberty (Bloch, Clemons, & Sperling, 1997) and youth with T1D generally require more insulin and have more difficulty keeping stable blood glucose levels (Rogers, 1992). Because of this unpredictability, it is recommended youth in this age group check their blood glucose levels more frequently.

Parental involvement. In addition to biological mechanisms which can disrupt metabolic control, socially, adolescents typically seek increased separation from parents in favor of peer relationships (Anderson & Coyne, 1991). Declines in parental involvement may occur as parents make adjustments to a child's developing autonomy, with pubertal status, and movement towards the teenage years signaling these changes (Steinberg, 1987). During this time, adjustments may occur in both parenting behaviors and expectations and youth are given greater freedom and decision making and spend less time with parents (Barber, 2002; Larson & Richards, 1991). A premature transfer of disease care responsibility from parents to youth may occur as a function of age rather than successful disease management and often results in a decline in disease care behaviors (Anderson, Ho, Brackett, Finkelstein & Laffel, 1997). Wysocki and colleagues (1996) found youth with too much self-care autonomy relative to their psychological maturity had poorer adherence and more hospitalizations compared to youth with more appropriate autonomy. However, when parents remain involved in diabetes management tasks, youth may bypass normative deterioration in disease care behaviors and metabolic control (Anderson, Auslander, Jung, Miller & Santiago, 1990; Wysocki, et al. 1996).

Conflict. Both general and diabetes-specific conflict between parents and youth typically increase in adolescence and are associated with poorer disease care (Anderson, Vangsness, Connell, Butler, & Laffel, 2002). Higher diabetes conflict is significantly related to metabolic control when controlling for age, sex, disease duration, and blood glucose monitoring adherence (Anderson et al., 2002). Although parental involvement is critical during adolescence, it can also lead to increased conflict and stress and ought to be based on adolescent's developmental level. Improper parental involvement can escalate conflict and decrease healthy adolescent disease care behaviors (Anderson et al., 2002).

Any and all of these factors may result in poorer disease care and ultimately, poorer metabolic control in adolescence (Anderson, Ho, Brackett, Finkelstein & Lafell, 1997; Holmes et al., 2006). Because the period of adolescence is a time of rapid change, unique factors in this age group that impact the reliability and validity of the measures must be examined. Age-related changes in disease care can be a particular challenge to accurately measure during adolescence. Examination of developmental differences in disease care responsibility and parental monitoring are important potential moderators to consider in assessment of the reliability and validity of disease care measures. In the current study, age will be used as a proxy for developmental maturity.

Responsibility for Disease Care

As youth begin the developmental transition into adolescence, parents become less involved in disease care. Frequently, decreased parental responsibility for diabetes disease care is associated with poorer disease care and metabolic control. Holmes and colleagues (2006) used Structural Equation Modeling (SEM) to empirically test a biopsychosocial model of predictors of youth disease care behaviors and metabolic control. The Diabetes Family Responsibility Questionnaire (DFRQ) measured parent and youth perceptions of responsibility for disease care behaviors. More youth responsibility was related to less frequent and/or shorter, exercise periods, fewer daily blood glucose tests, and fewer meals/snacks. In a predominantly middle class sample, parents retained more responsibility for dietary composition and nutrition was less affected by age. Age alone was the primary determinant of parental transfer of responsibility (Holmes et al., 2006) which can be problematic in light of poorer disease outcomes as youth begin the transition to adolescence (Anderson, Ho, Brackett, Finkelstein & Lafell, 1997).

In contrast, Hegelson, Reynolds, Siminerio, Escobar, & Becker (2008) found shared responsibility measured by the DFRQ, rather than sole youth or parent responsibility, is optimal for youth psychological and physical health. However, both youth and parent report of parent responsibility were associated with poorer disease care behavior. Shared responsibility is associated with better metabolic control among older but not younger adolescents and has implications for the treatment of youth and their families (Hegelson et al., 2008). Shared responsibility may assume greater importance among older adolescents. Although families may believe responsibilities should shift from parent to youth in adolescence, continued parental involvement in diabetes care is important, although sole parental responsibility appears unfavorable (Hegelson et al., 2008).

Numerous published studies report age-related declines in metabolic control along with less parental and shared responsibility in adolescence; however, psychometric studies of disease care measures typically do not account for level of parental responsibility (Anderson, Auslander, Jung, Miller & Santiago, 1990; Johnson, 1993; Lagreca et al., 1995; Wysocki, 2006). If disease care responsibility varies in this age group, it is critical to account for this variability to better describe adolescent disease care and to better clarify the psychometric properties of disease care measures. If age and disease care responsibility do impact the validity of a measure, these factors should be taken into account when the psychometric properties of assessment measures are examined.

Parent/Youth Agreement

In pediatric psychology research, parents and youths are the most common dyad studied as parent's play an integral role in youth's diabetes care. As discussed previously, because level of parent responsibility shifts in adolescence and youth take more control of their diabetes,

parent/youth agreement is an important factor to consider in the assessment of the psychometric properties of disease care measures. Previous diabetes research has examined the relation between parents and youths through Pearson's *r* correlation coefficients to determine how strongly the pairs of variables are related (Hanson et al., 1989; 1992, Harris et al., 2000; Iannotti, 2006, Johnson, 1986). Low parent/youth correlations often are construed as inaccurate or unreliable descriptions by one or both informants (Garrison & Earls, 1985). Achenbach, McConaughy & Howell (1987) suggest this interpretation neglects the possibility that different informants contribute valid but different information. Low cross-informant correlations may indicate that target behaviors differ from one situation to another, or one person to another, rather than the informants' reports are invalid and unreliable. For disease care behaviors in youth with T1D, parent/youth agreement is assumed to be low due to the unique factors of this developmental age range.

The scoring of parent and youth measures is another factor to examine in measurement of disease care. Disease care measures frequently rely upon parent and youth informants to describe youth behaviors. Responses often are tallied as two scores averaged, parent and youth scores reported separately, or a compilation of decisions according to *a priori* rules. Averaged scores may result in loss of precision from each informant report but allow for a single composite score of disease care. Separate parent and youth scores provide valuable information about different perceptions of disease care, but do not allow for a composite score of disease care. Despite the inherent difficulties of combining multi-informant reports, multi-source disease care information is important in adolescence in light of decreased parental responsibility and less knowledge of their child's disease management. Thus, even low parent/youth correlations may be informative

(Achenbach et al., 1987). In the current study, separate parent, youth and parent/youth aggregate data will be considered when appropriate to allow for a better picture of disease care.

Measurement of Disease Care Behaviors

Disease care is related to metabolic control in a number of studies, but not perfectly. Inconsistent correlations might reflect differences in the assessment and quantification of disease care and the complex nature of factors related to metabolic control (Hanson et al., 1996; Johnson, 1986; Johnson et al., 1992). Although greater adherence to disease care behavior recommendations is necessary for better metabolic control, objective measurement of disease care behaviors remains problematic. Little consistent evidence exists in the literature on the comparative reliability and validity of different disease care measures (Stewart, Emslie, Klein, Haus, & White, 2005) and no widely-adopted measure is in use that successfully measures all aspects of diabetes disease care. Yet there is a tremendous need to validly and reliably assess disease care behaviors as a precursor to better metabolic control and as a potential point of intervention for youth in poorer control.

Available T1D disease care measures vary in assessment of content domains, time intervals, and presentation formats. Domains differ according to the goals of each specific measure and broadly can be separated into reports of meta-behaviors and actual behaviors. Meta-behaviors are diabetes behaviors that are less easily quantified by frequency, intensity, or time, but are important to daily care. Meta-behaviors are more complex than actual behaviors and ask more complex questions such as how often blood glucose is checked when one feels high or low, or what one usually does to treat low blood sugar reactions. Actual behaviors are typically quantified by frequency and duration, as in the 24-hr Diabetes Interview, (Johnson et al., 1986) and include frequency of blood glucose checks, nutritional intake, and exercise.

Temporal assessment. Evaluation of behavioral and biomedical outcomes across similar time periods is an imperative but elusive goal in diabetes behavioral medicine research (Hanson et al, 1996). The physiological outcome, HbA1c, reflects an average blood glucose level over the previous two- to three-months. To optimally describe the relation between metabolic control and disease care behaviors, each should be evaluated across similar time intervals (Hanson et al., 1986). However, such an extended time frame makes accurate recall quite difficult or even impossible. Many measures choose the advantage of a shorter time period for more accurate recall and assume behaviors reported from shorter time periods extrapolate or represent average behavior over a longer time frame (Freund, Johnson, Silverstein & Thomas, 1991).

Presentation format. A variety of presentation formats exist for disease care measures. Questionnaires are most common and easily administered, but are prone to halo effects. See Table 1 for a description of commonly used questionnaires. Interview styles typically assess recall from a specific day or time period in precise detail, but often present an extensive time burden to train examiners and score (see Table 2; Hanson et al., 1996). Diary methods record disease care activities not accessible via observation and significantly reduce memory problems, but compliance is often poor and vulnerable to recall problems (Johnson, 1993). Further it is often difficult to verify information entered. In contrast, electronic monitors such as blood glucose monitors are able to increase precision by recording the exact time and date that an action is performed. However, not all aspects of disease care can be measured electronically, such as dietary behaviors. Refer to Quittner, Modi, Lemanek, levels-Landis and Rapoff (2008) for more information about diary methods and electronic monitors.

Table 1

Description of Commonly Used Disease Care Questionnaires

Criteria:	**Diabetes Behavior Rating Scale** (DBRS; Iannotti, 2006)	**Diabetes Regimen Adherence Questionnaire** (DRAQ; Bond,1992)	**Self-Care Inventory** (SCI; LaGreca et al., al, 1988; Wysocki et al.1996)
Evidence-Based Assessment Classification	Not assessed	Well-established	Well- established
Number of Items	37-pump, 36- non pump	15	14
Respondents	Parent and youth	Youth only	Parent and youth
Age Range (in years)	11-18	8-17	5-17
Temporal Range	1 week	Not reported	1-2 weeks
Time to Administer	~6-7 minutes	Not reported	~5 minutes
Content	Described in subscales	Testing for sugar, taking injections according to schedule, diabetic diet	Blood glucose testing and monitoring, insulin and food regulation, exercise, and emergency precautions
Subscales	Daily Prevention Behaviors, Modification of Diabetes Care Plan, Intervention Behaviors and Other Diabetes Care Practices	None	None
Scaling	0-5 scale	1-5 scale	1-5 scale
Assessment of Different Insulin Regimens	Yes	No	Yes
Scoring	148 for pump and 144 for non-pump- calculated as a proportion of the maximum possible score with higher scores reflecting higher adherence	15-75 with higher scores indicating greater adherence	Scores are summed and divided by the total number of items in each scale and multiplied by 10

Table 2

Description of Commonly Used Disease Care Interviews

Criteria	**24-hr Diabetes Interview** (24-hr; Johnson, 1986)	**Disease Care Adherence Interview** (DCAI; Hanson et al, 1989; 1992; 1996)	**Diabetes Self-Management Profile** (DSMP; Harris et.al. 2000)
Evidence-Based Assessment Classification	Well-established	Approaching well-established	Not reported
Number of Items	Semi-structured	15, semi structured	23
Respondents	Parent and youth	Parent and youth	Parent and youth
Age Range	6-19	10-20	11+
Temporal Interval	24-hrs	Not reported	3-months
Administration Time (in minutes)	~25	~20	~15-30
Content	Insulin injections, blood glucose monitoring, nutritional intake, and exercise	Dietary behaviors, insulin adjustment, glucose testing, hypoglycemia preparedness	Insulin administration/ dose adjustment, blood glucose monitoring, exercise, diet and management of hypoglycemia
Subscales	Same as content	Same as content	None
Assesses Different Insulin Regimens	Yes	Not reported	Yes
Scoring Range	Frequency, duration and percentage of calories and carbs are calculated	4- to 5-point scales- total score reflects a summation of the item scores with a possible score of 41	Higher scores suggest more optimal adherence

Two of the most widely used presentation formats, questionnaires and interview style, will be discussed in more detail in this paper. Two widely used measures in these formats, The Diabetes Behavior Rating Scale (Iannotti, 2006), a self-report questionnaire, and an interview technique, the 24-hr Diabetes Interview (Johnston, 1986) will be described further and examined in more depth with particular attention paid to their psychometric properties.

Psychometric Indices

Multiple indices can determine whether a measure adequately assesses a construct of interest (Kazdin, 2003). Psychometric characteristics refer to the reliability and validity evidence of a measure (Kazdin, 2003). While reliability refers to the consistency of a measure, validity refers to the content and whether the measure assesses a domain of interest (Kazdin, 2003). Multiple statistical tools are available to evaluate the psychometric soundness of a measure. Relevant tools include test-retest reliability, internal consistency, criterion-related validity, incremental validity, convergent validity, and external validity.

Reliability. Test-retest reliability refers to the stability of test scores over time and correlates scores from one administration of the test with scores on the same instrument after an elapsed time interval (Kazdin, 2003). The stability of a measured variable depends in part on the measurement interval(Garson, 2010). Test-retest reliability generally uses the Spearman Brown Split-Half Reliability Coefficient to estimate full test reliability based on split-half reliability measures (Garson, 2010). By convention, .80 is considered “adequate”, and .90 is considered “good” reliability (Garson, 2010). Test-retest reliability is sometimes criticized because of short intervals between administration times, practice effects, and maturation; nevertheless it remains a widely used measure of reliability (Garson, 2010). For disease care measures, test-retest reliability is important because multiple measurement points are frequently used in clinical care

to assess change over time. It is vital to have a measure that shows stability over time so changes assessed are due to changes in actual behavior versus instability of the measure.

Internal consistency. Internal consistency refers to the degree of consistency or homogeneity of the items within a scale. Different reliability measures are used to assess internal consistency, such as split half reliability, Kudar Richardson 20 formula, and Cronbach's alpha (Kazdin, 2003). Cronbach's alpha is the most common form of internal consistency used which is reported as a reliability coefficient (Garson, 2010). Cronbach's alpha will generally increase as the intercorrelations among test items increase, and is thus known as an internal consistency estimate of reliability of test scores. Because intercorrelations among test items are maximized when all items measure the same construct, Cronbach's alpha is indirectly indicates the degree to which a set of items measures a single unidimensional latent construct. The average intercorrelation among test items is affected when skewed. Thus, whereas the modal intercorrelation among test items will equal zero when the set of items measures several unrelated latent constructs, the average intercorrelation among test items will be greater than zero in this case. Indeed, several investigators have shown alpha can take on quite high values even when the set of items measures several unrelated latent constructs (Cronbach, 1951; Green, Lissitz & Mulaik, 1977; Revelle, 1979; Schmitt, 1996; Zinbarg, Yovel, Revelle & McDonald, 2006). As a result, alpha is most appropriately used when the items measure different substantive areas within a single construct. When the set of items measure more than one construct, coefficient omega hierarchical is more appropriate (McDonald, 1999; Zinbarg, Revelle, Yovel & Li, 2005). Alpha equals zero when a true score is not measured and only error remains. An alpha of one indicates all items measure the true score (Garson, 2010). By convention, a cutoff of .60 is considered "lenient", with .70 considered "adequate" and .80 considered "good" internal

consistency (Garson, 2010). A "high" value of alpha is often used (along with substantive arguments and possibly other statistical measures) as evidence that the items measure an underlying (or latent) construct.

Criterion-related validity. Criterion-related validity is the degree of effectiveness with which performance on a test or procedure predicts performance in a real-life situation; i.e.., a good correlation between a score on an intelligence test such as the Scholastic Aptitude Test and one's 4-year college grade point average. Predictive validity is one type of criterion-related validity and refers to the correlation of an item at time of measurement with performance on another measure or criterion in the future (Kazdin, 2003). A high correlation shows a measure can predict a variable or outcome of interest. In the current study, longitudinal data is not available, so another type of criterion-related validity, concurrent validity, will be used. Concurrent validity occurs when the criterion measures are obtained at the same time as the test scores (Kazdin, 2003). This indicates the extent to which the test scores accurately estimate an individual's current state with regards to the criterion. For example, on a test that measures levels of depression, the test would be said to have concurrent validity if it measured the current levels of depression experienced by the test taker. The magnitude of the correlations obtained from criterion-related validity studies is usually not high. "Good" criterion-related validity correlations are above .35. Higher values are occasionally seen and lower values are very common (American Educational Research Association, 1999). Disease care measures frequently use metabolic control, or HbA1c as a criterion, with values that range from .33 to .35 for frequently used disease care measures (Bond et al., 1992; Harris et al., 2000; Iannotti, 2006).

Convergent validity. Convergent validity refers to the level of agreement between independent measures of the same construct (Kazdin, 2003). Generally, similar measures have

moderate to high convergent validity such as the Diabetes Behavior Rating Scale and the Diabetes Self-Management Profile (r = .72; Ianotti, 2006). If the measures converge, it indicates the two measures assess the same construct (Kazdin, 2003). Because correlations between two measures may be due to the similarities in presentation format, multiple presentation formats that use different administration modalities are recommended to avoid 'source error' effects (Kazdin, 2003). Correlations above .40 provide evidence of "good" convergent validity (Kazdin, 2003). If two disease care measures correlate too highly, it might be futile to use both in tandem as they are measuring the same concept. However, if one measure assesses meta-behaviors over a longer time period while the other assesses actual behaviors over the previous day, the measures could correlate moderately but still have unique variance. Thus, it might be beneficial to use both in tandem.

Incremental validity. Sechrest (1963) argues psychological tests intended for applied clinical use must yield improved prediction over results garnered from commonly obtained assessment data. Incremental validity poses a fairly stringent test of validity in that an outcome must be better than chance, and must demonstrate additive value beyond other relevant sources of information (Hunsley & Meyer, 2003). Incremental validity should be required for any new measure, but is rarely investigated (Hunsley & Meyer, 2003). Evaluation of incremental validity also is indicated when an existing measure is revised or updated (Haynes & Lench, 2003). Incremental validity can also provide a useful comparison of test measures. For example, the Self-Care Inventory (SCI; Lewin et al., 2005) was evaluated as an adjunctive disease care measure to another questionnaire, the Diabetes Self-Management Profile (DSMP). However, the SCI provided no incremental predictive validity in HbA1c over the DSMP and no additional variance was explained in metabolic control beyond that explained by the DSMP. For the disease

care measures examined in this study, if one measure, or both, provide incremental validity over the other, it will be further evidence of the relative advantages of the measures.

External validity. External validity refers to the generalization of results to other populations, settings, times, measures and characteristics beyond those experimentally investigated (Kazdin, 2003). If a measure can hold true for other people places or times, the findings are said to be more generalizable. Numerous threats to external validity include sample characteristics, stimulus characteristics, settings, multiple-treatment interference, novelty, and timing (Kazdin, 2003). Refer to Kazdin (2003) for a further description on threats to external validity. In this study, external validity will be examined by examining Pearson's *r* correlation coefficients between pump and non-pump users. If pump users and non-pump users differ in adherence scores when examining the disease care measures, the measures might not be generalizable to different insulin regimens. However, low correlations might be indicative of factors such as higher SES and parental income levels in pump users compared to non-pump users as described previously.

Questionnaires

Questionnaires are the most common self-report method used to assess disease care behaviors (Rapoff, 1999). Typically closed- (forced choice) or open-ended (written-in answers) questions are employed to elicit information. Questionnaires generally represent a subjective appraisal of typical or average behaviors over one to two months (Hanson et al., 1996). Descriptions of commonly used questionnaires are presented in Table 3 along with their appropriate age ranges, number of items, subscales and scoring.

The Diabetes Behavior Rating Scale (DBRS)

The *Diabetes Behavior Rating Scale (DBRS;* Iannotti, 2006) will be examined in greater depth because of its promising psychometric properties, use of questionnaire format, and ease of administration (measure attached in Appendix A). The DBRS is a diabetes-specific questionnaire used to assess disease care behaviors and meta-behaviors via parent and youth report over the last seven days, with separate insulin pump and non-pump formats. The original DBRS was a 35-item, self-administered, fixed-choice survey (McNabb et al., 1994). Limitations of the original scale included lack of items addressing insulin administration with the pump, the need for updating to current intensive regimens, and following adherence to an "ideal regimen" vs. more flexible regimens of the pump. To address the first two limitations, items were revised to reflect current diabetes management practices and a pump version of the DBRS was developed, replacing insulin injection specific items with items relevant to administration of insulin with an insulin pump. Administration time is approximately seven minutes, per questionnaire for parent and youth. Subscales include *Daily Prevention Behaviors, Modification of Diabetes Care Plan, Intervention Behaviors,* and *Other Diabetes Care Practices.*

Reliability and stability. Iannotti and colleagues (2006) report evidence of acceptable parent/youth agreement, test-retest reliability, internal consistency, predictive validity, and convergent validity (Table 3). To this date, no factor analysis has been published. In previous literature, no subscale data were reported. The normative sample included 146 participants (81 females) with a mean age of 14.8 years (range 11-18, *SD*, 1.98) and mean disease duration of 8.3 years. The sample was 81.5% white and representative of the clinic populations from which it was drawn (compared to 33% minority in the US; US Census Bureau, 2008). Forty-five percent used insulin pumps, and fifteen percent used multiple daily injections or basal-bolus regimens.

Test-retest reliability was acceptable for parents (r = .71) and youth (r = .71). Internal consistency was good in parent (α = 84) and youth (α = 84) versions. Parent/youth agreement was moderate (r = .48). No significant differences were found between adherence levels reported by parents and youths in total scores. Convergent validity was demonstrated with the Diabetes Self-Management Profile, another measure of regimen adherence for both parents (r = 0.72, p < .0001) and youths (r = 0.74, p < .0001). The DBRS was negatively related to youth age in both parent (r = -.20, p < .05), and youth reports (r = -.18, p < .05) such that older youth and their parents reported poorer adherence. Parent and youth responses were moderately related to HbA1c (r = -.35, p < .0001 and -.34, p < .0001 respectively). Level of disease care responsibility was not evaluated in the normative data.

Table 3

Psychometric Properties of Commonly Used Disease Care Questionnaires

Psychometric Properties:	**Diabetes Behavior Rating Scale** (DBRS; Iannotti, 2006)	**Diabetes Regimen Adherence Questionnaire**(DRAQ; Bond et al., 1992)	**Self-care Inventory** (SCI; LaGreca et al., 1988)
Parent/Youth Agreement	r = .48	Not assessed	Not assessed
Test-Retest Reliability	1-week, r = .71	Not assessed	2-week, r = .77
Internal Consistency	α = .84	α =.78-.80	α =.76-.97
Criterion-Related Validity	Significantly related to HbA1c (r = -.35).		Good correlations reported between 24-hr and HbA1c
Convergent Validity	Significantly related to the DSMP (r =.72)	Good correlations with health beliefs (r = -.29- -.33) and social problem-solving skills (r = .43– .64)	Good correlations reported between 24-hr and SCI

Interview Format

Interview formats of disease care assessment vary widely. Typically, interview formats collect behavioral samples of disease care over a 24-hour to 7-day period and reflect a type of time sampling in which recall of specific behaviors is assessed in precise detail and is assumed to extrapolate to averaged behavior (Hanson et al., 1996). The psychometric properties of different interview measures are presented in Table 4 along with information about age ranges, number of items, subscales and scoring.

24-Hour Diabetes Interview (24-hr)

The 24-hour Diabetes Interview was chosen for further study because the American Psychological Association (APA) of Pediatric Psychology's Evidence Based Assessment (EBA) task force considers the 24-hr "well-established" and for its strong psychometric properties (measure attached in Appendix B). Criteria for a well-established measure require at least two research teams publish sufficient information that evaluates the measure (Freund, Johnson, Silverstein & Thomas, 1991; Johnson, 1986; Quittner, Modi, Lemanek, levers-Landis, & Rapoff, 2008). The 24-hr Diabetes Interview is a disease care measure which focuses on highly specific behavior over a relatively brief time period. Administration time is approximately 25 minutes, per interview for parent and youth, separately. The 7 disease care domains include: *Frequency of Blood Glucose Monitoring, Meal/Snack Frequency, Percentage of Daily Calories from Fats and Carbohydrates, Exercise Duration, Exercise Frequency, and Insulin Regimen.*

Administration. Parent and youth are interviewed on two separate occasions within a two week period. Although previous research conducted three interviews, only two were feasible in the current study due to the numerous questionnaires and interviews participants were asked to complete (1.5-2 hours for baseline data in RCT). Subjects are asked to recall the previous 24-

hours in temporal sequence from the time the youth arises. The interviewer records all diabetes relevant activities which include: Insulin injections, blood glucose monitoring, nutritional intake, and exercise. If not mentioned, an interviewer prompts youth and parents to describe specific disease care activities. The interviewer asks the time, who performed the behavior, whether an adult observed, and whether a parent or adult discussed the activity with the youth for each disease care behavior. Blood glucose levels are obtained from a youth's blood glucose meter read by the parent or youth. Details about duration and intensity of physical activity are gathered. Interviewers gather specific nutritional information and include information about serving sizes, brand names, condiments, etc. Participants are asked if an insulin pump, basal bolus, or multiple injections are used. If basal/bolus or injections, participants are asked the average number of times insulin is injected per day.

Scoring. After the interview is complete, parent and youth data from the same 24-hour period are entered into a food scoring system (Food Pro; Food Processor SQL, 2009) to calculate nutrition information, with as much detail as possible. A set of detailed decision rules established by Johnson (1986) reconcile differences in parent/youth report for combined data: Minor discrepancies between parent and youth report sources (e.g., youth and parent report different product brands) are resolved by use of the parent report if the parent observed, and the youth report if parent did not. When parents do not observe youth's behavior, it is difficult to give precise estimates of what the youth actually ate. However, if parents observe, estimates of portion sizes might be more accurate than those provided by youths (Johnson, 1986). If a parent does not observe a meal, different amounts of food intake reported by parents and youths are reconciled by use of a youth's report. If a parent observes, discrepancies are reconciled by taking the larger of the two amounts to account for systematic underreporting of food consumption

which occurs (Johnson, 1986). An exception to this rule is when an unrealistic quantity of food is reported, the more realistic report is adopted. Additional food items reported by parents are not included if a parent does not observe and are included if the parent observes. Additional items reported by youth are included regardless of whether a parent observes. Rules for additional food items and how to reconcile different amounts of food were chosen because youths and parents often underestimate food consumption due to errors of memory (Carter, Sharbaugh, & Stapell, 1981). Major discrepancies are resolved by an interviewer's best judgment. However, if an interviewer does not indicate, discrepancies are handled on a case by case basis but typically use parent report for youth 12-years or younger. For youth 13-years and older, youth report is used because older teenagers have decreased parental contact compared to younger youth and can describe their meals with more detail and accuracy. Parent and youth reports are averaged for exercise type, exercise duration, calories, injection and glucose monitoring behaviors. Because parents are not aware of all of their youth's activities and because younger youth in particular may "forget" a glucose test conducted by a parent (Johnson, 1986), a statement by either that the activity occurred is accepted for exercise frequency and glucose testing frequency.

Training. Because of the complexity of the 24-hr, a labor intensive training procedure and scoring guidelines is involved. Assessors must become highly familiar in interview procedures and obtaining specific details about every disease care behavior and whether the parent observed or discussed behaviors with youth. If a detail is left out by parent or youth, assessors must probe parents or youth in depth to get all possible information. In scoring the 24-hr, assessors must be careful in filling out all details in the form correctly and accurately. If assessors leave out the information in both assessment and scoring of the interview, errors will emerge that impact the reliability and validity of the measure. For scoring of nutritional

information, subjective choice is involved when scorers must enter nutritional data into the nutrition program and assessors must be trained in picking options most closely related to what youth actually eat. However, detailed decision rules aid in making this choice more objective.

Reliability and stability. Freund, Johnson, Silverstein & Thomas (1991) and Johnson (1986) report evidence of acceptable parent/youth agreement, test-retest reliability, and predictive validity (Table 4). The normative sample includes 168 participants (47% female) with age range of 6-19 years, with diabetes duration of 1-17 years (no means reported). The sample was 88% Caucasian. Insulin pump administration method was not reported. Test-retest reliability was good for most measures (r = 06. - .76). The test-retest reliability of each subscale is reported in Table 4. Parent/youth agreement was good to excellent (r > .80) for most of 13 separate behaviors reported (Johnson et al., 1986). Agreement was influenced by youth age, with higher parent/youth agreement found in the 10-12 (r =.50 - .80) and 13-15 (r =.54 - .83) year age groups compared to the 6-9 (r = -.23 - .79) and 16-19 (r = -.04 - .92) ages. With more 24-hr assessments, Freund and colleagues (1991) found nine interviews (r = .59 - .94) yielded higher parent/youth agreement than three interviews (r = .33 - .94). For the sample as a whole, parent/youth agreement remained stable over the 90-day course of the study. Parent/youth agreement was higher for all weekdays (r = .47 - .95) compared to weekend days (r = .09 - .90). Dietary (r = .45 - .77) and glucose testing (r =.72 - .76) measures exhibited greater stability than exercise (r =.37 - .74) and injection (r =.06 - .71) behaviors. Parent/youth agreement of each subscale is reported in Table 4. Predictive validity results have been variable for disease care measures (r = .03-20; Hanson et al., 1986*).* Level of disease care responsibility was not evaluated in the normative data.

Table 4

Psychometric Properties and Description of Commonly Used Disease Care Interviews

Criteria:	**24-hr Diabetes Interview** (24-hr, Johnson, 1986)	**Disease care Adherence Interview** (DCAI; Hanson et al, 1989; 1992;1996)	**Diabetes Self-Management Profile** (DSMP; Harris et. al, 2000)
Parent/Youth Agreement	Injection regularity, *r* =.62- .74 Injection interval, *r* =.72- .87 IM timing, *r* =.64- .79 Reg IM timing, *r* = 27-.40 Exercise frequency, *r* =.65– .75 Exercise duration, *r* =.57– .89 Exercise type, *r* =.64– .76 Eating frequency, *r* = 65– .78 Calories consumed, r =.66– .76 Calories from carbs, *r* = .71– .76 Calories from fat (%), *r* =.73– .77 Concentrated sweets, *r* =.59– .83 Glucose testing, *r* =.72-.76	*r* = .95-.98 for youth and parents	*r* = .61-.95
Test-Retest Reliability	Injection regularity, *r* = 06- .35 Injection interval, *r* = .38- .49 Injection-meal timing, *r* = .58-.71 Regularity IM timing, *r* = 24- .31 Exercise frequency, *r* = .40- .63 Exercise duration, *r* = .42– .74 Exercise type, *r* =.37- .48 Eating frequency, *r* = .63- .77 Calories consumed, *r* =.67- .74 Calories from carbs, *r* = .45– .61 Calories from fat (%), *r* = 51– .63 Concentrated sweets, *r* =.51– .53 Glucose testing, *r* =.72– .76	3-month, *r* = .70 6-month, *r* = .68–.70 1-year, *r* = .71	3-month *r* = .67
Internal Consistency	n/a	*r* = .76 for youths, r = .87 for parents	*r* = .76 for youths and parents
Criterion-Related Validity	Better adherence was moderately associated with better metabolic control for some disease care measures, *r* = .03-.20	Correlations between the SCI and HbA1c , *r* = .20-.28	Not assessed
Convergent Validity	Not assessed	Not assessed	Diet, *r* = -.27, BG, *r* =-.37, insulin administration, *r* = -.25

Examination of the DBRS and 24-hr

Although both the DBRS and 24-hr assessment measures appear promising, the relative advantages and disadvantages of each disease care measure ought to be weighed. The DBRS is relatively new while the 24-hr has been designated by APA as a well-established evidence based assessment measure with acceptable reliability and validity. However, the DBRS shows promising psychometric properties and further replication of the reliability and validity of the measures is necessary to establish further evidence base (Iannotti, 2006). While both measures show relatively lower correlations in parent/youth agreement, level of agreement is consistent with other similar measures and may be an artifact of the developmental age range.

Relation with HbA1c. Although the DBRS is related to HbA1c (r = -.35; Iannotti, 2006) the association between the 24-hr and HbA1c is moderate (r = .03-.20; Johnson, 1986; Johnson et al., 1992). Replication and generalization of the psychometric results with a different subject sample could move toward the goal of establishing a 'gold standard' of disease care measurement.

Disease care measurement. The DBRS and 24-hr measures may be complementary and good adjuncts to one another. The DBRS contains mostly meta-behaviors, while the 24-hour measures actual behaviors. For example, the DBRS covers a wide range of disease care activities and includes activities not typically measured, i.e., disease care during illness, specific behaviors in regard to supplies, testing blood glucose levels when the level is high or low, questions are included about collaboration with healthcare professionals and regimen adjustments (Schilling, Grey & Knafl, 2002). In contrast to the meta-behaviors of the DBRS which provide vaguer estimates of composite prevention and modification behaviors, the 24-hour is able to identify actual behaviors such as frequency of disease care behaviors of blood glucose monitoring,

insulin administration, nutrition and that can be targeted for intervention. The DBRS has four subscales, in addition to a total score, which allows assessment of both unitary and multidimensional constructs; in contrast one disadvantage of the 24-hr is its lack of a unitary construct.

Administration and scoring. While the DBRS is designed to be administered once, the 24-hr conducts two to three separate interviews which increases the validity of the behavioral sample. Both the DBRS and the 24-hr may be administered to multiple informants, parents and youths, which allow for comparison across respondents. While the DBRS includes a relatively short administration time of approximately 7 minutes, the 24-hr takes approximately 25 minutes to complete per individual, and can be difficult to administer efficiently in a busy clinical setting. The DBRS can be self-administered and is simple to score, while the 24-hr requires trained staff members to conduct interviews and relies upon a complex scoring system that is more prone to inconsistencies. However, the complexity and richness of information in the 24-hr provides a wealth of data. To further increase accuracy, the 24-hr assesses a self-described 'typical' day that does not include hospitalizations, illness, or difficult pump site changes. The DBRS is susceptible to social desirability issues present in all questionnaires, while the 24-hr interview queries parents and youths separately to reduce bias yet allow direct comparison of different informants' reports of the same day. The DBRS and 24-hr both assesses quantifiable behavior with its circumscribed focus on a specific time period rather than a global estimate or perceptions of behavior over a longer period; however, the 24-hr is a more specific time period.

The DBRS and 24-hr relative to other same-format measures. One of the common disadvantages of self-report questionnaires is the longer time period assessed; however, the recall burden of the DBRS is substantially reduced, with responses queried over the prior seven days,

an ideal time period for recall (Rudd, 1993). Further, the DBRS, unlike other questionnaires, uniquely assesses prevention behaviors as well as meta-cognitive knowledge of how to modify the disease care regimen. The DBRS has insulin pump and non-pump versions (Iannotti, 2006) while other questionnaires typically do not (Bond et al., 1992). These advantages of the DBRS have the potential to make it a cost-effective adjunct to the 24-hr to assess diabetes management. Last, the 24-hr is unique in that it is one of only a handful of interviews available that have established psychometric properties (Hanson et al., 1989; Harris et al., 2000; Johnson, 1986).

Statement of Problem

Two measures of diabetes disease care, the Diabetes Behavior Rating Scale (DBRS) and the 24-hr Diabetes Interview (24-hr) were evaluated to develop a better understanding of each measure alone and in combination and facilitate development of a "gold standard" of diabetes care measurement. The utility of different disease care measurement techniques, questionnaire versus interview, was examined via assessment of their psychometric properties. A replication of the reliability and validity of each measure was undertaken. Further, these analyses were extended to report the psychometric properties of the two previously undescribed pump and non-pump versions and the subscales of the DBRS. First, the reliability of each measure was determined by examination of the measure's test-retest reliability, internal consistency, and parent/youth agreement. Test-retest reliability was examined for the 24-hr for parent and youth to determine the stability of the scores at multiple measurement points. Internal consistency was examined for the DBRS to determine the degree of consistency or homogeneity of the items within a scale. Parent/youth agreement examined possible differences in parent and youth report of disease care. Next, the validity of the measures was determined. Concurrent validity assessed the correlation of each measure with metabolic control. Convergent validity determined the

correlation between the two disease care measures. Next, the incremental validity of the two measures was assessed as correlates of metabolic control to determine if the measures, alone or together, account for more variance. The external validity of each measure was compared with intensive and conventional insulin regimens. Last, the study uniquely examined parent/youth shared responsibility as a moderator between age and metabolic control. If disease care responsibility influences the relationship between age and metabolic control, this factor should be considered in the examination of disease care measures.

Hypotheses

Reliability

1. ***Test-Retest Reliability*:** Good ($r > .90$) test-retest reliability will be found for subscales of the 24-hr for parent, youth and parent/youth aggregate data. Retest information is not available for the DBRS.
2. ***Internal Consistency*:** The subscales of the DBRS will show good ($r > .80$) internal consistency for parent and youth report, separately. Internal consistency analyses were not conducted for the 24-hr.
3. ***Parent/Youth Agreement*:** Good parent/youth agreement ($r > .80$) will be found for the total score of the DBRS and subscales of each disease care measure for parent and youth.

Validity

4. ***Concurrent Validity*:** The subscales of each disease care measure will show good concurrent validity ($r > .35$) of metabolic control for parent, youth and parent/youth aggregate data.

5. ***Convergent Validity*:** The convergent validity of the two disease care measures will show a high correlation ($r > .40$) between the two measures.
6. ***Incremental Validity*:** The incremental validity of the two measures will be evaluated to determine through hierarchical multiple regression to determine the relative contribution of each disease care measure in their association with metabolic control.
7. ***External Validity*:** The external validity of each measure will be established by a comparison of pump and non-pump regimens.

Moderators

8. ***Correlations:*** As a first step in the moderation analyses, correlations between parent/youth responsibility, age and HbA1c will be conducted. Parent/youth responsibility will be significantly associated with age. More shared parent/youth responsibility and older youth age will be associated with better metabolic control.
9. ***Parent/Youth Responsibility Moderator*:** More parent/youth shared responsibility will moderate the deleterious effect of older youth age on poorer disease care and metabolic control.

Method

Participants

Participants are youth age 11 to 14 and an accompanying parent seen at one of two metropolitan pediatric endocrinology clinics. Data was utilized from a baseline assessment of an ongoing Randomized Controlled Trial (RCT) of parental involvement in youth's diabetes disease care. Inclusion criteria requires diagnosis of T1D for a minimum of one-year prior to enrollment,

no other major chronic illness or injury, fluency in reading and writing English, and the absence of developmental disorders (e.g. Down's Syndrome, Autism).

Procedure

Potential participants and their parents or guardians serving as parents received a recruitment letter for a baseline assessment in a RCT designed to prevent deterioration in youth diabetes disease care. Per, IRB protocol detailed in HB10557, after the recruitment letter was sent by the clinic physician, parents were contacted by telephone and invited to participate. If parents and youths agreed, assessments were scheduled in conjunction with youths' upcoming endocrinology appointments. After written informed parental consent and youth assent was obtained, a trained research assistant interviewed parent and youth separately and distributed questionnaire packets. Upon completion, each family received $25 for participation.

Measures

Demographic information. Youth demographic information was obtained from questionnaires completed by the parent who accompanied youth to a baseline evaluation. Information was obtained about youth's gender, date of birth, socioeconomic status (SES), ethnicity, age of disease onset, and disease duration.

Metabolic control. Metabolic control was measured by glycosylated hemoglobin (HbA1c) level at the time of a youth's medical appointment. HbA1c provides an estimate of average blood glucose concentration over the previous two- to three-month period. The American Diabetes Association (2009) recommends HbA1c levels for children to be < 8.0% and < 7.5% for adolescents. Poorer metabolic control is indicated by higher HbA1c levels. HbA1c levels were obtained by medical chart review.

Perceptions of youth disease care responsibility. The Diabetes Family Responsibility Questionnaire (DFRQ; Anderson, Auslander, Jung, Miller, & Santiago, 1990) measures an individual's perceptions of responsibility for different diabetes care behaviors: parent, youth or shared parent/youth responsibility. The DFRQ consists of 21 items related to responsibility for specific diabetes care behaviors. Parents and youth indicate their perceived level of responsibility for each task. Possible responses for each item along a 5-point scale include: "parent initiates responsibility for this almost all of the time", "parent unusually takes or initiates responsibility", "child and parent share responsibility about equally", "child usually takes or initiates responsibility", "child takes or initiates responsibility almost all of the time". Each item contributes to one of four different subscales: *General, Communication, Frequency,* and *Hypoglycemia*. Scores range from 20-105, with higher scores indicative of greater youth responsibility. Appropriate internal consistency was established for the original 17-item version (α = .71 - .86; Auslander, Anderson, Bub, Jung, & Santiago, 1990) and is similar with the current version (α = .82; Streisand, Swift, Wickmark, Chen, & Holmes, 2005).

Diabetes Behavior Rating Scale (Iannotti et al., 2006). The Diabetes Behavior Rating Scale (DBRS) is a self-report measure of youth disease care which utilizes report by parent and youth, separately. Subscales include Daily Prevention Behaviors (0 = *never* to 4 = *always*), Modification of Diabetes Care Plan (0 = *never* to 5 = *five times*), Intervention Behaviors (0 = *never* to 4 = *always*), and Other Diabetes Care Practices (0 = *never* to 5 = *five times*). The youth and parent insulin pump version contains 37 items with a possible total score of 148. The youth and parent non-pump version for insulin injections contains 36 items with a possible total score of 144. To provide comparable insulin pump and non-pump/injection results, scores will be calculated as a proportion of the maximum total possible score (0.06-1.00), in which higher

scores demonstrate greater adherence to disease care. Previous analyses by Iannotti et al. (2006) reveal the mean total score to be .75 +/- .10, with acceptable internal consistency ($\alpha = .84$), test-retest reliability ($r = .71$), and parent/youth agreement ($r = .48$).

24-Hour Diabetes Interview. The 24-hour Diabetes Interview (24-hr) measures youth's disease care behaviors. Parents and youths are interviewed separately and asked to report all diabetes-relevant behaviors from the previous 24-hour period in temporal order upon arising in the morning. Because the 24-hr is a complex interview, research assistants were trained by reading a detailed manual with specific interview prompts, and practicing a minimum of two to three times with an advanced graduate student or until all manual guidelines are followed and an 85% accuracy level is reached. In addition, advanced graduate students observed the first two interviews administered to participants to establish research assistant's adherence to all 24-hr rules. Data include each instance of blood glucose monitoring, insulin injections or bolus, nutritional intake and physical activity. In the event a parent or youth omits diabetes care information, research assistants will be instructed to prompt with specific, nonjudgmental questions. Data reported by parents and youths will be analyzed according to an established set of decision rules (Johnson, 1986) that yield a description of seven disease care behaviors: *Frequency of Blood Glucose Monitoring, Meal/Snack Frequency, Percentage of Daily Calories from Fats and Carbohydrates, Exercise Duration, Exercise Frequency,* and *Insulin Regimen*. Decision rules will help resolve discrepancies between parent and youth reports. Pearson product-moment correlations for each measured variable suggest acceptable agreement between parent/youth dyads (Johnson, 1986). The test-retest reliability varies by age and by diabetes care behavior over a three-month interval (e.g., blood glucose monitoring, $r = .72$ to .76; diet

behaviors, r = .45 to .77; exercise behaviors, r = .37), which indicates generally appropriate temporal stability (Freund, Johnson, Silverstein & Thomas, 1991). See Table 4 for greater detail.

Results

Results included data from 250 youths and their parents. Demographic and disease characteristics of the sample are reported in Table 5. The sample was 51% males with a mean age of 12.8 years (*SD* = 1.2). Participants were predominantly middle class with a Hollingshead Index score of 46.4 (11.8); 69% Caucasian, 19% African American, 6% Asian/Asian American, 2% Hispanic, and 4% other. Participants had a mean onset age of 7.7 years (*SD* = 3.3) and a mean disease duration of 5.1 years (*SD* = 3.1). Mean HbA1c of youths was 8.8 (*SD* = 1.7) and parents reported 43% of youths used insulin pump regimens, 21% used basal/bolus regimens, and 36% used 2-3 insulin shots a day. On average, youths and parents reported blood glucose checks four times a day, approximately four meals per day, exercise at least once a day, insulin injections or boluses three to four times per day, and meal composition of 35% fats and 50% carbohydrates. Means and standard deviations for the total scores and subscales of the DBRS and the 24-hr separated by informant source are reported in Table 6.

Table 5

Demographic and Disease Characteristics. Mean scores reported with (SD)

N	250
Gender	
Male	51%
Female	49%
Age (yrs)	12.8 (1.2)
Hollingshead Index of SES	46.4 (11.8)
Ethnicity	
Caucasian	69%
African-American	19%
Asian/Asian-American	6%
Hispanic	2%
Other	4%
Disease Onset (yrs)	7.7 (3.3)
Disease Duration (yrs)	5.1 (3.1)
HbA1c	8.8 (1.7)
Insulin Regimen	
Pump	43%
Basal Bolus	21%
2-3 Shots	36%

Table 6

DBRS and 24-hr: Means and Standard Deviations by Informant Source

	Parent	*Youth*	*Parent/Youth Aggregate*
DBRS			
Total Score	.67 (.11)	.63 (.13)	.65 (.10)
Daily Prevention Behaviors	.68 (.12)	.68 (.12)	.68 (.11)
Modification of Diabetes Care Plan	.51 (.26)	.47 (.26)	.50 (.21)
Intervention Behaviors	.71 (.19)	.67 (.19)	.69 (.15)
Other Diabetes Care Practices	.76 (.13)	.71 (.19)	.74 (.13)
24-hr			
Frequency of Blood Glucose Monitoring	4.3 (1.5)	4.3 (1.5)	4.3 (1.4)
Meal/Snack Frequency	4.1 (1.0)	4.2 (0.9)	4.1 (0.8)
Exercise Duration	53.8 (44.4)	57.8 (74.5)	54.9 (55.2)
Exercise Frequency	1.1 (0.7)	1.2 (0.8)	1.1 (0.7)
Insulin Regimen	3.5 (1.0)	3.6 (1.1)	3.5 (.1.0)
Percentage of Daily Calories from Fats[a]	-	-	35.2 (7.4)
Percentage of Daily Calories from Carbs[a]	-	-	49.5 (8.4)

Note. [a]Separate parent and youth values are not calculated for this variable. Aggregate data is created via decision rules detailed in Johnson et al., 1986

Reliability Hypotheses

Hypothesis 1: Test-retest reliability of the 24-hr. Pearson's *r* correlations assessed test-retest intraclass correlations of the seven subscales of the 24-hr: *Frequency of Blood Glucose Monitoring, Meal/Snack Frequency, Exercise Duration, Exercise Frequency, Insulin Regimen, and Percentage of Daily Calories from Fats and Carbohydrates*. Retest data was not available for the DBRS. Data were only used for the 212 participants where both parent and youth interviews were completed. All measures yielded significant Pearson's *r* correlation coefficient's ranging from $r = .20\text{-}.60$. However, the correlations were lower than recommended to possess adequate psychometric properties ($r > .80$; Garson, 2010). Refer to Table 7 for a list of correlations by informant source.

Table 7

Hypothesis 1: Test-Retest Reliability of the 24-hr by Informant Source (N = 212)

	Parent	*Youth*	*Parent/Youth Aggregate*
Frequency of Blood Glucose Monitoring	.52**	.60**	.60**
Meal/Snack Frequency	.33**	.38**	.46**
Exercise Duration	.35**	.24**	.36**
Exercise Frequency	.34**	.20**	.29**
Insulin Regimen	.38**	.57**	.58**
Percentage of Daily Calories from Fats[a]	-	-	.20**
Percentage of Daily Calories from Carbs[a]	-	-	.26**

Note. *p <.05. **p <.01.

[a]Separate parent and youth values are not calculated for this variable. Aggregate data is created via decision rules detailed in Johnson et al., 1986

Hypothesis 2: Internal consistency of the DBRS. Cronbach's alpha tested internal consistencies for the total score and four subscales of the DBRS (*Daily Prevention Behaviors, Modification of Diabetes Care Plan, Intervention Behaviors and Other Diabetes Care Practices*) for the pump and non-pump versions of the scale for parent and youth report. Because versions of the questionnaires differ by insulin regimen, internal consistencies for each are reported separately. In addition, parent and youth measures are different, thus aggregate data was not reported. Consistent with the previous literature (Iannotti, 2006), Cronbach's alpha for total score was adequate ($\alpha > .70$; Garson, 2010) to high ($\alpha > .80$; Garson, 2010) for parent ($\alpha = .76$-$.79$) and youth ($\alpha = .79$-$.82$) report. Cronbach's alpha for the DBRS subscales ranged from inadequate to high for parent ($\alpha = .42$-$.81$) and youth ($\alpha = .59$-$.78$) report. See Table 8 for sample based Cronbach's alpha values. In contrast to the questionnaire style of the DBRS, the 24-hr interview assesses multidimensional constructs, thus internal consistencies were not examined.

Table 8

Hypothesis 2: Internal Consistency of the DBRS by Pump Status and Informant Source (N = 212)

	Cronbach's alpha	
	Parent *(N = 104)*	Youth *(N = 109)*
Pump		
Total Score	.76	.82
Daily Prevention Behaviors	.70	.70
Modification of Diabetes Care Plan	.75	.78
Intervention Behaviors	.64	.68
Other Diabetes Care Practices	.46	.59
Non-Pump	Parent *(N = 141)*	Youth *(N = 141)*
Total Score	.79	.79
Daily Prevention Behaviors	.77	.71
Modification of Diabetes Care Plan	.81	.76
Intervention Behaviors	.66	.61
Other Diabetes Care Practices	.42	.62

Hypothesis 3: Parent/youth agreement. Parent/youth agreement was assessed with Pearson's *r* correlation coefficients between parent and youth scores of the DBRS and the 24-hr. Consistent with previous literature (Iannoti, 2006; Johnson, 1986), correlations between subscales and total scores were lower than good (r >.80; Garson, 2010) for the DBRS (r = .28-.57) and the 24-hr (r = .48-.67), with the exception of the 24-hr Frequency of Blood Glucose Monitoring subscale (r = .80). Parent/youth agreement was not calculated for the 24-hour Diabetes Interview subscales of Percentage of Daily Calories from Fat and Carbohydrates because reports were combined prior to data entry via established decision rules (Johnson, 1986). Refer to Table 9 for a complete list of the correlations for parent and youth for each of the subscales and the total score of the DBRS.

Table 9

Hypothesis 3: Parent/Youth Agreement for DBRS and 24-hr

	Pearson's r correlation coefficients
DBRS (N = 250)	
Total Score	.38**
Daily Prevention Behaviors	.57**
Modification of Diabetes Care Plan	.28**
Intervention Behaviors	.30**
Other Diabetes Care Practices	.28**
24-hr[a] *(N = 246)*	
Frequency of Blood Glucose Monitoring	.80**
Meal/Snack Frequency	.51**
Exercise Duration	.48**
Exercise Frequency	.64**
Insulin Regimen	.67**

Note. *p <.05, **p<.01

[a]Separate parent and youth values are not calculated for the variables of Percentage of Daily Calories from Fats and Carbohydrates. Data is combined prior to data entry via decision rules in Johnson (1986)

Validity Hypotheses

Hypothesis 4: Concurrent validity. Pearson's *r* correlations conducted between HbA1c and the total score and subscales of the DBRS and the 24-hr were near good ($r > .35$; American Educational Research Association, 1999) and similar to previous literature (Bond et al., 1992; Harris et al., 2000; Iannotti, 2006; Johnson, 1992). Concurrent correlations between HbA1c and the DBRS total score were significant for parents *(*$r = -.30$) youths *(*$r = -.28$) and parent/youth aggregate data *(*$r = -.33$). Correlations among the subscales varied by informant source with the highest correlations found between HbA1c and the Daily Prevention Behaviors subscale ($r = -.28$ - $-.33$) of the DBRS and the Frequency of Blood Glucose Monitoring subscale ($r = -.28$ - $-.33$) of the 24-hr. See Tables 10 and 11 for means, standard deviations and intercorrelations between HbA1c and the subscales of the two disease care measures by informant source.

Multiple regression analyses were conducted to determine the best linear combination of the subscales of the DBRS and the 24-hr by informant source. Assumptions of linearity, normally distributed errors, and uncorrelated errors were checked and met.

Parent, youth, and parent/youth aggregate data of the DBRS were significantly related to HbA1c; $F(4, 239) = 10.03$, $p < .001$, $R^2 = .14$ for parents, $F(4, 239) = 5.45$, $p < .001$, $R^2 = .08$, for youths, and $F(4, 239) = 9.59$, $p < .001$, $R^2 = .14$ for parent/youth aggregate data. Regression analyses revealed 14%, 8% and 14% of the variance in HbA1c was explained by each of the models respectively. Beta weights in Table 12 display Daily Prevention Behaviors significantly contributing to the model for parents, youths and parent/youth aggregate data.

Parent, youth, and parent/youth aggregate data of the 24-hr were significantly related to HbA1c; $F(7, 236) = 7.27$, $p < .001$, $R^2 = .18$ for parents, $F(7, 236) = 5.70$, $p < .001$, $R^2 = .15$, for youths, and $F(7, 238) = 7.25$, $p < .001$, $R^2 = .18$ for parent/youth aggregate data. Regression

analyses revealed 18%, 15% and 18% of the variance in HbA1c was explained by each of the regression models respectively. The beta weights in Table 13 suggest Frequency of Blood Glucose Monitoring and Meal/Snack Frequency are the only significant contributors to HbA1c in all regression models.

Table 10

Hypothesis 4: Concurrent Validity of the DBRS and HbA1c: Means, Standard Deviations, and Intercorrelations by Informant Source (N= 244)

	M (SD)	1	2	3	4
Parent					
HbA1c	8.8 (1.7)	-.30**	-.22**	-.25**	-.0
DBRS					
1. Prevention	.68 (.12)	-	.16**	.19**	.19**
2. Modification	.51 (.26)		-	.36**	.08
3. Intervention	.71 (.19)			_	.12*
4. Other	.76 (.13)				-
Youth					
HbA1c	8.8 (1.7)	-.28**	-.10	-.09	-.07
DBRS					
1. Prevention	.68 (.12)	-	.27**	.19**	.36**
2. Modification	.47 (.26)		-	.39**	.28**
3. Intervention	.67 (.19)			_	.25**
4. Other	.71 (.19)				-
Parent/Youth Aggregate					
HbA1c	8.8 (1.7)	-.33**	-.20**	-.21**	-.06
DBRS					
1. Prevention	.68 (.11)	-	.26**	.22**	.28**
2. Modification	.50 (.21)		-	.38**	.21**
3. Intervention	.69 (.15)			_	.27**
4. Other	.74 (.13)				-

Note. *p <.05, **p <.01

Table 11

Hypothesis 4: Concurrent Validity of the 24-hr and HbA1c: Means, Standard Deviations, and Intercorrelations by Informant Source (N= 244).

Variable	*M (SD)*	1	2	3	4	5	6	7
Parent								
HbA1c	8.8 (1.7)	-.33**	-.21**	-.12*	-.07	-.21**	.24**	-.22**
24-hr								
1. Blood Glucose	4.3 (1.5)	-	.22**	.13	.07	.55**	-.13*	.09
2. Eating Frequency	4.1 (1.0)		-	-.00	.11*	.20**	-.04	.07
3. Exercise Duration	53.8 (44.4)			-	.24**	.08	.03	-.01
4. Exercise Frequency	1.1 (0.7)				-	.08	-.11*	.09
5. Insulin Regimen	3.5 (1.0)					-	-.11*	.15**
6. % Fat	35.3 (7.4)						-	-.72**
7. % Carbs	49.5 (8.4)							-
Youth								
HbA1c	8.8 (1.7)	-.28**	-.21**	-.06	-.04	-.20**	.24**	-.22**
24-hr								
1. Blood Glucose	4.3 (1.5)	-	.21**	.06	.01	.54**	-.18**	.09
2. Eating Frequency	4.2 (1.0)		-	-.04	.06	.18**	-.16**	.14*
3. Exercise Duration	57.8 (74.5)			-	.14*	.01	.06	-.01
4. Exercise Frequency	1.2 (0.8)				-	-.06	-.09*	.03
5. Insulin Regimen	3.6 (1.1)					-	-.07	.13*
6. % Fat	35.3 (7.4)						-	-.72**
7. % Carbs	49.4(8.4)							-
Parent/Youth Aggregate								
HbA1c	8.8 (1.7)	-.32**	-.24**	-.10	-.06	-.23**	.24**	-.22**
24-hr								
1. Blood Glucose	4.3 (1.4)	-	.22**	.09	.03	.57**	-.16*	.09
2. Eating Frequency	4.1 (0.8)		-	-.03	.12*	.17**	-.11*	.12*
3. Exercise Duration	54.9 (55.2)			-	.24**	.08	.03	-.01
4. Exercise Frequency	1.1 (0.7)				-	.00	-.11*	.07
5. Insulin Regimen	3.5 (.1.0)					-	-.10	.15**
6. % Fat	35.3 (7.4)						-	-.72**
7. % Carbs	49.5 (8.4)							-

Note. *p <.05, **p <.01

Table 12

Hypothesis 4: Concurrent Validity of the DBRS and HbA1c: Simultaneous Multiple Regression Analysis Summary by Informant Source (N = 244)

Variable	*B*	*SE*	β	*p*
Parent				
Constant	12.21	.78		.00**
Daily Prevention Behaviors	-3.61	.86	-.26	.00**
Modification of Diabetes Care Plan	-.77	.41	-.12	.06
Intervention Behaviors	-1.41	.57	-.16	.014*
Other Diabetes Care Practices	.64	.76	.05	.40
Youth				
Constant	11.47	.65		.00**
Daily Prevention Behaviors	-3.91	.92	-.29	.00**
Modification of Diabetes Care Plan	-.09	.45	-.01	.84
Intervention Behaviors	-.37	.58	-.04	.52
Other Diabetes Care Practices	.43	.59	.05	.47
Parent/Youth Aggregate				
Constant	12.56	.79		.00**
Daily Prevention Behaviors	-4.6	.99	-.30	.00**
Modification of Diabetes Care Plan	-.67	.53	-.08	.21
Intervention Behaviors	-1.42	.72	-.13	.05*
Other Diabetes Care Practices	.95	.82	.08	.24

Note. *p <.05, **p <.01

Table 13

Hypothesis 4: Concurrent Validity of the 24-hr: Simultaneous Multiple Regression Analysis Summary by Informant Source (N = 244)

Variable	*B*	*SE*	β	*p*
Parent				
Constant	-10.80	1.48		
Frequency of Blood Glucose Monitoring	-.27	.08	-.25	.00**
Meal/Snack Frequency	-.22	.10	-.14	.03*
Exercise Duration	-.00	.00	-.10	.11
Exercise Frequency	.02	.14	.01	.90
Insulin Regimen	-.03	.11	-.02	.79
Percentage of Daily Calories from Fat	.03	.02	.14	.10
Percentage of Daily Calories from Carbs	-.02	.02	-.08	.33
Youth				
Constant	11.10	1.58		
Frequency of Blood Glucose Monitoring	-.22	.08	-.20	.01**
Meal/Snack Frequency	-.23	.11	-.12	.05*
Exercise Duration	-.00	.00	-.06	.36
Exercise Frequency	-.02	.13	-.01	.86
Insulin Regimen	-.07	.11	-.05	.54
Percentage of Daily Calories from Fat	.03	.02	.12	.20
Percentage of Daily Calories from Carbs	-.02	.02	-.10	.29
Parent/Youth Aggregate				
Constant	11.41	1.53		
Frequency of Blood Glucose Monitoring	-.26	.09	-.23	.00**
Meal/Snack Frequency	-.31	.12	-.16	.01**
Exercise Duration	-.00	.00	-.09	.15
Exercise Frequency	.00	.15	.00	.99
Insulin Regimen	-.07	.12	-.04	.58
Percentage of Daily Calories from Fat	.03	.02	.13	.15
Percentage of Daily Calories from Carbs	-.02	.02	-.08	.34

Note. *p <.05, **p <.01

Hypothesis 5: Convergent validity. Convergent validity was assessed to determine the correlation between the two disease care measures. To provide more stable measures of the underlying abilities, scores from each tests' subscales were aggregated to form unit-weighted *z* scores of the DBRS (M = .00, SD = 1.00) and the 24-hr (M = .00, SD = 1.00) for parent/youth combined data. The two disease measures demonstrated significant inter-correlation, r = .28, p < .01, but lower than the predicted correlation coefficient (r > .40; Kazdin, 2003) suggesting each measured distinct elements of disease care.

Hypothesis 6: Incremental validity. Incremental validity was assessed for the two disease care measures via hierarchical multiple regression. For each value, parent and youth scores were combined to create a composite score. Linear hierarchical regressions were conducted to investigate the unique variance in HbA1c associated with the 24-hr and the DBRS. The DBRS alone significantly related to HbA1c, $F(4, 241) = 9.86$, $p < .001$, $R^2 = .14$; addition of the 24-hr improved the association, $\Delta F(11, 234) = 4.33$, $p < .001$, $\Delta R^2 = .10$. Conversely, the 24-hr alone, also significantly related to HbA1c, $F(7, 238) = 7.47$, $p < .001$, $R^2 = .18$; addition of the DBRS improved the association, $\Delta F(11, 234) = 4.54$, $p < .01$, $\Delta R^2 = .06$. The entire group of variables was significantly related to HbA1c, $F(11, 234) = 6.69$, $p < .001$, $R^2 = .24$. DBRS Daily Prevention Behaviors (B = .19), and 24-hr Frequency of Blood Glucose Monitoring (B = -.14) and Meal/Snack Frequency (B = -.13) behaviors were the only significant contributors to the model (See Tables 14 and 15). A separate multiple regression of the three factors alone was significantly related to HbA1c, $p < .01$, $R^2 = .17$ (See Table 16).

Table 14

Hypothesis 6: Incremental Validity of the DBRS (Step 1 and 2) and the 24-hr (Step 2) with HbA1c: Hierarchical Multiple Regression Analysis Summary by Informant Source (N = 245)

Variable	*B*	*SE*	β	*p*
Step 1				
Constant	12.63	.79		.00**
DBRS				
Daily Prevention Behaviors	-4.66	.99	-.30	.00**
Modification of Diabetes Care Plan	-.68	.53	-.09	.20
Intervention Behaviors	-1.44	.71	-.13	.05*
Other Diabetes Care Practices	.95	.81	.08	.24
Step 2				
Constant	13.46	1.65		.00**
DBRS				
Daily Prevention Behaviors	-2.92	1.03	-.19	.01**
Modification of Diabetes Care Plan	-.64	.52	-.08	.22
Intervention Behaviors	-1.30	.71	-.12	.07
Other Diabetes Care Practices	1.15	.80	.09	.15
24-hr				
Frequency of Blood Glucose Monitoring	-.17	.09	-.14	.05*
Meal/Snack Frequency	-.26	.12	-.13	.04*
Exercise Duration	-.00	.00	-.09	.15
Exercise Frequency	-.03	.15	-.01	.86
Insulin Regimen	-.03	.12	-.02	.78
Percentage of Daily Calories from Fat	.02	.02	.10	.23
Percentage of Daily Calories from Carbs	-.02	.02	-.11	.21

Note. *p <.05, **p <.01

Table 15

Hypothesis 6: Incremental Validity of the 24-hr (Step 1 and 2) and the DBRS (Step 2) with HbA1c: Hierarchical Multiple Regression Analysis Summary by Informant Source (N = 245)

Variable	*B*	*SE*	β	*p*
Step 1				
Constant	11.45	1.52		.00**
24-hr				
Frequency of Blood Glucose Monitoring	-.26	.08	-.23	.00**
Meal/Snack Frequency	-.31	.12	-.16	.01*
Exercise Duration	-.00	.00	-.09	.15
Exercise Frequency	.00	.15	.00	.98
Insulin Regimen	-.07	.12	-.04	.58
Percentage of Daily Calories from Fat	.03	.02	.13	.15
Percentage of Daily Calories from Carbs	-.02	.02	-.09	.32
Step 2				
Constant	13.46	1.65		.00**
24-hr				
Frequency of Blood Glucose Monitoring	-.17	.09	-.14	.05*
Meal/Snack Frequency	-.26	.12	-.13	.04*
Exercise Duration	-.00	.00	-.09	.15
Exercise Frequency	-.03	.15	-.01	.86
Insulin Regimen	-.03	.12	-.02	.78
Percentage of Daily Calories from Fat	.02	.02	.10	.23
Percentage of Daily Calories from Carbs	-.02	.02	-.11	.21
DBRS				
Daily Prevention Behaviors	-2.92	1.03	-.19	.01**
Modification of Diabetes Care Plan	-.64	.52	-.08	.22
Intervention Behaviors	-1.30	.71	-.12	.07
Other Diabetes Care Practices	1.15	.80	.09	.15

Note. *p <.05, **p <.01

Table 16

Hypothesis 6: Incremental Validity of the DBRS Daily Prevention Behaviors Subscale and the 24-hr Frequency of Blood Glucose Monitoring and Meal/Snack Frequency Subscales with HbA1c: Simultaneous Multiple Regression Analysis Summary by Informant Source (N = 245)

Variable	*B*	*SE*	β	*p*
Constant	13.17	.70		.00**
24-hr				
Frequency of Blood Glucose Monitoring	-.24	.07	-.21	.00**
Meal/Snack Frequency	-.27	.12	-.13	.03*
DBRS				
Daily Prevention Behaviors	-3.26	1.01	-.21	.00**

Note. *p <.05, **p <.01

Hypothesis 7: External Validity External validity of the DBRS and the 24-hr was determined by examining Pearson's *r* correlation coefficients between disease care measurement scores in pump and non-pump users. Means and standard deviations of pump and non-pump user's scores on disease care measures are presented in Table 17 and 18. Pearson's *r* correlation coefficients are presented in Table 19 and 20.

Separate regression analyses were conducted to determine if pump and non-pump users varied in their association with HbA1c for each of the disease care measures. Assumptions of linearity, normally distributed errors, and uncorrelated errors were checked and met. The DBRS, scores and their association with HbA1c varied between pump and non-pump users. For pump users, the DBRS did not significantly contribute to HbA1c for parents $F(4, 101) = 1.55$, $p = .20$, $R^2 = .06$, youth $F(1, 101) = 2.35$, $p = .06$, $R^2 = .09$, or parent/youth aggregate data, $F(4, 101) = 2.07$, $p = .09$, $R^2 = .08$. For non-pump users, the DBRS significantly contributed to HbA1c for parents $F(4, 133) = 7.40$, $p < .001$, $R^2 = .18$, youth $F(1, 133) = 2.97$, $p < .05$, $R^2 = .08$, and parent/youth aggregate data, $F(4, 133) = 6.73$, $p < .001$, $R^2 = .17$ (See Table 21).

In contrast, the 24-hr scores and their association with HbA1c did not vary depending on pump status. For pump users, the 24-hr significantly contributed to the model for parents $F(7, 97) = 3.32$, $p < .01$, $R^2 = .19$, youths $F(7, 99) = 4.00$, $p < .01$, $R^2 = .22$, and parent/youth aggregate data $F(7, 99) = 4.49$, $p < .01$, $R^2 = .24$. For non-pump users, the 24-hr disease care behaviors also significantly contributed to the model for parents $F(7, 130) = 5.16$, $p < .001$, $R^2 = .22$, youths, $F(7, 130) = 3.08$, $p < .01$, $R^2 = .14$ and parent/youth aggregate data $F(7, 130) = 4.43$, $p < .01$, $R^2 = .19$ (See Table 22).

Table 17

Hypothesis 7: External Validity of the DBRS with HbA1c: Means and Standard Deviations by Pump Status and Informant Source

	Pump	**Non-Pump**
Parent		
HbA1c	8.5 (1.3)	9.1 (1.8)
Daily Prevention Behaviors	.71 (.10)	.67 (.13)
Modification of Diabetes Care Plan	.52 (.25)	.51 (.27)
Intervention Behaviors	.74 (.17)	.69 (.20)
Other Diabetes Care Practices	.79 (.12)	.75 (.14)
Youth		
HbA1c	8.5 (1.3)	9.1 (1.8)
Daily Prevention Behaviors	.70 (.11)	.66 (.12)
Modification of Diabetes Care Plan	.51 (.26)	.45 (.25)
Intervention Behaviors	.70 (.19)	.65 (.19)
Other Diabetes Care Practices	.76 (.18)	.68 (.20)
Parent/Youth Aggregate		
HbA1c	8.5 (1.3)	9.1 (1.8)
Daily Prevention Behaviors	.70 (.10)	.66 (.11)
Modification of Diabetes Care Plan	.51 (.21)	.48 (.20)
Intervention Behaviors	.72 (.15)	.67 (.16)
Other Diabetes Care Practices	.77 (.11)	.71 (.14)

Table 18

Hypothesis 7: External Validity of the 24-Hr and HbA1c: Means and Standard Deviations by Pump Status and Informant Source

	Pump	**Non-Pump**
Parent		
HbA1c	8.5 (1.4)	9.1 (1.8)
Frequency of Blood Glucose	4.8 (1.6)	3.9 (1.4)
Eating Frequency	4.0 (1.0)	4.1 (1.0)
Exercise Duration	53.5 (56.7)	50.1 (49.9)
Exercise Frequency	0.9 (0.7)	1.0 (0.8)
Insulin Regimen	3.7 (1.1)	3.2 (0.9)
Percentage of Calories from Fats	35.1 (7.1)	35.4 (7.6)
Percentage of Calories from Carbs	50.3 (7.8)	48.9 (8.9)
Youth		
HbA1c	8.4 (1.3)	9.1 (1.8)
Frequency of Blood Glucose	4.8 (1.5)	4.0 (1.4)
Eating Frequency	4.2 (0.9)	4.2 (0.9)
Exercise Duration (min)	62.7 (86.4)	54.7 (64.4)
Exercise Frequency	1.1 (0.8)	1.2 (0.8)
Insulin Regimen	4.1 (1.1)	3.2 (1.0)
Percentage of Calories from Fats	35.1 (7.1)	35.3 (7.6)
Percentage of Calories from Carbs	50.2 (7.8)	48.9 (8.8)
Parent/Youth Aggregate		
HbA1c	8.4 (1.3)	9.1 (1.8)
Frequency of Blood Glucose	4.8 (1.5)	3.9 (1.3)
Eating Frequency	4.2 (0.9)	4.2 (0.9)
Exercise Duration (min)	62.7 (86.4)	54.6 (55.3)
Exercise Frequency	1.1 (0.8)	1.1 (0.7)
Insulin Regimen	4.1 (1.1)	3.3 (0.9)
Percentage of Calories from Fats	35.1 (7.1)	35.4 (7.6)
Percentage of Calories from Carbs	50.2 (7.8)	48.9 (8.9)

Table 19

Hypothesis 7: External Validity of the DBRS: Correlation with HbA1c by Pump Status and Informant Source

	Pump	**Non-Pump**
Parent		
Daily Prevention Behaviors	-.18*	-.32**
Modification of Diabetes Care Plan	-.17*	-.25**
Intervention Behaviors	-.12	-.28**
Other Diabetes Care Practices	.04	-.02
Youth		
Daily Prevention Behaviors	-.25**	-.26**
Modification of Diabetes Care Plan	.02	-.13
Intervention Behaviors	-.11	-.04
Other Diabetes Care Practices	-.04	-.03
Parent/Youth Aggregate		
Daily Prevention Behaviors	-.25**	-.34**
Modification of Diabetes Care Plan	-.09	-.24**
Intervention Behaviors	-.14	-.21**
Other Diabetes Care Practices	-.01	-.03

Note. *p <.05, **p <.01

Table 20

Hypothesis 7: External Validity of the 24-hr: Correlation with HbA1c by Pump Status and Informant Source

	Pump	Non-Pump
Parent		
Frequency of Blood Glucose Monitoring	-.18*	-.37**
Meal/Snack Frequency	-.30**	-.19*
Exercise Duration	-.00	-.20**
Exercise Frequency	-.05	-.10
Insulin Regimen	-.07	-.26**
Percentage of Daily Calories from Fats	.27**	.23**
Percentage of Daily Calories from Carbohydrates	-.15	-.24**
Youth		
Frequency of Blood Glucose Monitoring	-.21*	-.28**
Meal/Snack Frequency	-.32**	-.15*
Exercise Duration	.05	-.12
Exercise Frequency	-.15	.01
Insulin Regimen	-.04	-.17*
Percentage of Daily Calories from Fats	.30**	.23**
Percentage of Daily Calories from Carbohydrates	-.20**	-.24**
Parent/Youth Aggregate		
Frequency of Blood Glucose Monitoring	-.21*	-.34**
Meal/Snack Frequency	-.35**	-.20**
Exercise Duration	.03	-.17*
Exercise Frequency	-.11	-.05
Insulin Regimen	-.08	-.22**
Percentage of Daily Calories from Fats	.30**	.23**
Percentage of Daily Calories from Carbohydrates	-.20**	-.24**

Note. *p <.05 * *p <.01

Table 21

Hypothesis 7: External Validity of the DBRS: Simultaneous Multiple Regression Analysis Summary by Pump Status and Informant Source

Variable	*B*	*SE*	β	*p*	*B*	*SE*	β	*p*
	Pump				**Non-Pump**			
Parent								
Constant	9.90	1.18		.00**	12.84	1.04		.00**
Daily Prevention Behaviors	-2.19	1.37	-.17	.11	-3.98	1.11	-.29	.00**
Modification of Diabetes Care Plan	-.55	.56	-.10	.33	-1.03	.58	-.15	.08
Intervention Behaviors	-.44	.81	-.06	.59	-1.71	.78	-.19	.03*
Other Diabetes Care Practices	.93	1.13	.08	.41	.85	1.03	.07	.41
Youth								
Constant	10.71	.89		.00**	11.52	.94		.00**
Daily Prevention Behaviors	-3.25	1.23	-.28	.00**	-3.98	1.30	-.27	.00**
Modification of Diabetes Care Plan	.79	.59	.15	.18	-.66	.65	-.09	.31
Intervention Behaviors	-.84	.79	-.12	.29	-.11	.83	-.01	.89
Other Diabetes Care Practices	.31	.77	.04	.69	.84	.86	.09	.33
Parent/Youth Aggregate								
Constant	10.68	1.15		.00**	13.19	1.11		.00**
Daily Prevention Behaviors	-3.65	1.50	-.26	.02*	-4.94	1.32	-.31	.00**
Modification of Diabetes Care Plan	.20	.71	.03	.78	-1.48	.77	-.17	.06
Intervention Behaviors	-.95	1.01	-.10	.35	-1.63	.99	-.14	.10
Other Diabetes Care Practices	1.22	1.22	.10	.32	1.41	1.11	.11	.21

Note. *p <.05, **p <.01

Table 22

Hypothesis 7: External Validity of the 24-hr: Simultaneous Multiple Regression Analysis Summary by Pump Status and Informant Source

Variable	*B*	*SE*	β	*p*	*B*	*SE*	β	*p*
	Pump				**Non-Pump**			
Parent								
Constant	7.49	1.90		.00**	12.42	2.16		.00**
Frequency of Blood Glucose Mon.	-.11	.10	-.13	.25	-.34	.12	-.26	.01**
Meal/Snack Frequency	-.47	.14	-.35	.00**	-.23	.14	-.13	.11
Exercise Duration	-.00	.00	-.04	.64	-.00	.00	-.11	.20
Exercise Frequency	.08	.19	.04	.69	-.04	.19	-.02	.83
Insulin Regimen	.26	.15	.21	.08	-.19	.17	-.10	.26
% of Daily Calories from Fats	.06	.02	.32	.02*	.02	.03	.10	.40
% of Daily Calories from Carbs	.01	.02	.03	.80	-.02	.03	-.11	.37
Youth								
Constant	9.64	1.87		.00**	11.72	2.31		.00**
Frequency of Blood Glucose Mon.	-.12	.09	-.15	.17	-.30	.13	-.23	.02*
Meal/Snack Frequency	-.52	.16	-.36	.00**	-.16	.17	-.08	.33
Exercise Duration	.00	.00	.03	.79	-.00	.00	-.10	.24
Exercise Frequency	-.17	.16	-.10	.30	.07	.19	.03	.73
Insulin Regimen	.29	.13	.25	.03*	-.03	.19	-.02	.86
% of Daily Calories from Fats	.03	.02	.18	.17	.02	.03	.09	.50
% of Daily Calories from Carbs	-.01	.02	-.07	.56	-.03	.03	-.13	.31
Parent/Youth Aggregate								
Constant	9.13	1.81		.00**	12.55	2.23		.00**
Frequency of Blood Glucose Mon.	-.11	.09	-.13	.23	-.33	.13	-.24	.01*
Meal/Snack Frequency	-.67	.17	-.43	.00**	-.30	.17	-.14	.09
Exercise Duration	-.00	.00	-.03	.74	-.00	.00	-.11	.19
Exercise Frequency	-.05	.18	-.02	.81	.02	.21	.01	.93
Insulin Regimen	.38	.16	.28	.02*	-.16	.19	-.08	.41
% of Daily Calories from Fats	.05	.02	.25	.05	.02	.03	.10	.43
% of Daily Calories from Carbs	-.01	.02	-.05	.69	-.02	.03	-.11	.39

Note. *p <.05, **p <.01

Moderator Hypotheses:

Hypotheses 8: Correlations between parent/youth responsibility, age, and metabolic control. Pearson's *r* correlation analyses were conducted for parent/youth responsibility, age, and HbA1c (See Table 23). Consistent with the literature, there was a significant relation between age and parent/youth responsibility with parent, youth, and parent/youth aggregate data ($r = .14$, $p < .05$) reporting older youth taking more responsibility for disease care. In contrast to previous literature (Anderson, Ho, Brackett, Finkelstein & Laffel, 1997), parent/youth responsibility on the DFRQ was not correlated with HbA1c in parent ($r = -.02$, $p = .77$), youth ($r = -.05$, $p = .40$), or parent/youth aggregate ($r = -.04$, $p = .27$) reports. There was also a significant correlation between age and HbA1c with older youth obtaining higher (poorer) HbA1c scores in parent, youth, and parent/youth aggregate data ($r = .14$, $p < .05$).

Hypotheses 9: Parent/youth shared responsibility as a moderator of the relation between age and HbA1c. To determine the moderating effects of parent/youth responsibility on the relation between age and metabolic control, a hierarchical multiple regression was conducted (See Table 24). The independent variables of age and parent/youth responsibility were entered in the first block and age, parent/youth responsibility, and the two-way interactions were entered in the second block. Results indicated that age and parent/youth responsibility did not explain a significant incremental portion of the variance for parents $\Delta R^2 = .01$, $p = .12$, youth $\Delta R^2 = .00$, $p = .45$ or parent/youth aggregate data $\Delta R^2 = .01$, $p = .11$ in relation to poorer HbA1c (See Table 25). The lack of relation is consistent with the absence of a correlation between parent/youth responsibility and metabolic control. Thus the interactive effect of shared parent/youth responsibility on the relation between age and metabolic control was not supported.

Table 23

Hypothesis 8: HbA1c, Age, and DFRQ: Correlation Matrix

	Age	DFRQ	Age x DFRQ
Parent			
HbA1c	.14*	-.02	.04
Age	-	.31**	.69**
DFRQ		-	.90**
Youth			
HbA1c	.14*	-.05	.04
Age	-	.23**	.75**
DFRQ		-	.81**
Parent/Youth Aggregate Data			
HbA1c	.14*	-.04	.05
Age	-	.35**	.81**
DFRQ		-	.83**

*p <.05
**p <.01

Table 24

Hypothesis 9: HbA1c, Age, and DFRQ: Means and Standard Deviations by Informant Source

Parent	
HbA1c	8.8 (1.7)
Age	12.8 (1.2)
DFRQ	1.9 (0.3)
Age x DFRQ	24.8 (5.1)
Youth	
HbA1c	8.8 (1.7)
Age	12.8 (1.2)
DFRQ	2.2 (0.2)
Age x DFRQ	28.2 (4.5)
Parent/Youth Aggregate Data	
HbA1c	8.8 (1.7)
Age	12.8 (1.2)
DFRQ	2.1 (0.2)
Age x DFRQ	26.5 (4.3)

Table 25

Hypothesis 9: DFRQ as a Moderator of the relation between Age and HbA1c: Hierarchical Multiple Regression Analysis Summary by Informant Source

Variable	*B*	*SE*	β	*p*
Parent				
Step 1				
Constant	6.75	1.16		.00**
Age	.22	.09	.16	.02*
DFRQ	-.38	.36	-.07	.30
Step 2				
Constant	-4.91	7.58		.52
Age	1.14	.60	.84	.06
DFRQ	5.68	3.91	1.05	.15
Age x DFRQ	-.48	.31	-1.48	.12
Youth				
Step 1				
Constant	7.43	1.32		.00**
Age	.21	.09	.16	.02
DFRQ	-.61	.44	-.90	.17
Step 2				
Constant	-.07	9.96		.99
Age	.82	.80	.60	.31
DFRQ	2.77	4.46	.41	.54
Age x DFRQ	-.27	.36	-.74	.45
Parent/Youth Aggregate				
Step 1				
Constant	7.36	1.28		.00**
Age	.24	.09	.17	.01
DFRQ	-.76	.52	-.10	.14
Step 2				
Constant	-10.06	10.92		.36
Age	1.63	.87	1.20	.06
DFRQ	7.62	5.24	1.00	.15
Age x DFRQ	-.69	.42	-1.75	.11

Note. *p <.05, **p <.01

Discussion

A thorough examination of the psychometric properties of the Diabetes Behavior Rating Scale (DBRS) and the 24-hour Diabetes Interview (24-hr) alone and together displayed the relative advantages of each measure. The analyses of test-retest reliability (Hypothesis 1), internal consistency (Hypothesis 2) and parent/youth agreement (Hypothesis 3) replicated and extended the previous literature with a unique examination of the reliability of the DBRS subscales and the pump versus non-pump versions. Concurrent validity (Hypothesis 4) analyses revealed both measures are related to HbA1c, the gold standard in the assessment of metabolic control. External validity (Hypothesis 7) analyses illustrated the 24-hr is more flexible for use with all insulin regimens, while the DBRS may be more useful for youth on basal/bolus regimens or multiple daily injections. Although the potential moderator of parent/youth responsibility as measured by the DFRQ was explored and deemed not significant (Hypothesis 9), correlations revealed significant relations between both parent/youth responsibility and HbA1c and age, which indicated that older youth take more responsibility for disease care and have poorer HbA1c (Hypothesis 8). Convergent (Hypothesis 5) and incremental (Hypothesis 6) validity analyses found both measures provide unique variance in HbA1c. Within those measures, the Daily Prevention Behaviors subscale of the DBRS and the Frequency of Blood Glucose and Meal/Snack Frequency subscales of the 24-hr were the only significant predictors, suggesting the possibility of a briefer, multi-source, multi-method measure. The following sections will review each specific hypothesis in greater detail.

Test-Retest Reliability (Hypothesis 1)

Test-retest reliability analyses examined the stability of the 24-hr across two administrations. Similarly to previous literature (Johnson, 1986), test-retest reliability for the 24-

hr was r = .20-.60, which was relatively lower than recommended for adequate psychometric properties (r > .80; Garson, 2010; See Table 7). DBRS data was not examined. To reduce participant burden in the context of the current clinical research study, two 24-hr interviews were conducted versus three in previous literature (Johnson, 1986). Although an increased number of interviews increases parent/youth agreement (Freund, 1991), to date, no study has examined if interview number impacts test-retest reliability. In the current study, 24-hr test-retest reliability was lower than previous literature. Small changes in actual behavior from one administration to the next may have reduced reliability more in two versus three interviews. For example, if youth typically eat a healthy diet and on one occasion of the interview happened to eat a larger percentage of calories from fats than usual, this would skew the data more if a lower frequency of interviews were conducted.

Although the DBRS was not examined in the current study due to practical considerations, previous DBRS test-retest reliability (r = .71) reported by Iannotti and colleagues (2006) was relatively higher than the 24-hr. Possible differences between disease care measures may lie in content domains. Compared to more stable questionnaire traits such as the meta-behaviors of the DBRS (i.e. "In the last seven days were blood sugars tested every time your child ate?") the 24-hr measures actual disease care behaviors that are more sensitive and vary between two 24-hour periods (i.e. number of blood glucose checks on two separate days), particularly with the advent of more flexible pump regimens. Although this sensitivity may result in less reliable scores from one administration to the next, the results might be more accurate than the meta-behaviors of questionnaires with relatively vaguer answers that are prone to halo effects.

Internal consistency (Hypothesis 2)

Internal consistency is a measure of the degree of consistency or homogeneity of items within the DBRS. Internal consistency was α = .76-.82 in the overall score which displayed adequate to high internal consistency (α = .70-.80*;* Garson, 2010) and displayed variable adequacy in the DBRS subscales, α = .42-.81. See Table 8. In contrast, the 24-hr is a multivariate disease care measure that collects data in seven distinct areas versus the correlated items of a questionnaire; thus, it was not appropriate to examine the internal consistency of the 24-hr subscales (Johnson, Freund, Silverstein, & Hanson; 1990). Internal consistency is a critical factor in establishing the reliability of disease care questionnaires and was similar to previous literature (Iannotti, 2006).

Parent/Youth Agreement (Hypothesis 3)

Parent/youth agreement was examined to determine the concordance between parent and youth scores. Overall, parent/youth concordance was r = .28-.57 for the DBRS and r = .48-.67 for the 24-hr which was relatively lower than recommended for adequate psychometric properties (r > .80*,* Garson, 2010). The only exception was the 24-hr Frequency of Blood Glucose Monitoring subscale (r = .80) which was adequate. See Table 9. Low parent/youth concordance rates are consistent with previous research in this age group when parents become less involved in disease care as youth make the transition into adolescence. Therefore, lower scores might be more indicative of this developmental age range versus the reliability of the measures. However, higher parent/youth agreement was consistently found in the 24-hr (r = .48-.80) compared to the DBRS (r = .28-.57), which suggests measurement of more tangible disease care behaviors is associated with higher agreement between informants. Consistent with previous research, the 24-hr Frequency of Blood Glucose Monitoring subscale was the only subscale that

demonstrated adequate parent/youth agreement (Achenbach, 1997). Further, youth and their parents had electronic blood glucose meter data available to assist with recall and increase precision with the exact time, date, and number of times an action was performed (Quittner, 2008).

Parent/youth concordance rates reveal youths and parents vary in their reports of disease care behaviors, but vary less in reports of tangible disease care behaviors such as those on the 24-hr. Identification of subscales that display high parent/youth agreement and an interview with one informant versus both could reduce interviewer burden, which is particularly important in clinical research. For example, it may be superfluous for parents and youths to both read identical blood glucose numbers from their meter if both reports are similar. In subscales where parent/youth agreement is lower, examination of separate parent and youth scores also provides valuable information about different perceptions of disease care. If parent/youth agreement is discrepant, it might be important to determine which informant is more accurate and choose that informant to reduce interview burden. One way to determine more accurate informants is to determine their relation with HbA1c. For example, if parent scores on a disease care measure correlate more highly with HbA1c than youth scores, clinicians might choose to only use parent report. In some cases, it might also be useful to examine aggregate data when appropriate for a composite index of disease care (Achenbach, 1997). For example, if parents report youth ate 2000 calories and youth reported 3000, an average of 2500 might allow for a more accurate view of actual behavior. The 24-hr decision rules are one method to examine aggregate data in a way that allows reports of disease care behaviors to be more accurate.

Concurrent validity (Hypothesis 4)

Concurrent validity, or the degree to which each measure was related to metabolic control, typically ranges from r = .33 to .35 for available disease care measures (Iannotti, 2006; Bond et al., 1992; Harris et al., 2000). Overall, concurrent validity was r = .28-.33 for the DBRS total score, r = .00-.33 for the DBRS subscales and r = .04-.32 for the 24-hr subscales which was relatively lower than recommended for adequate psychometric properties (r = .80, Garson, 2010). The DBRS and the 24-hr both display significant and relatively similar associations with HbA1c which suggests they could be used interchangeably. See Tables 9-13. Significant associations with HbA1c, the gold standard in the assessment of metabolic control, are critical in establishing adequate concurrent validity of disease care measures.

Convergent validity (Hypothesis 5)

Convergent validity, or the level of agreement between the DBRS and the 24-hr was r = .28, lower than recommended for adequate psychometrics (r > .40; Kazdin 2002). The unique variance revealed in the incremental validity analyses explains partially why the convergent validity hypothesis was not supported and suggests both measures assess unique aspects of disease care. Measures with different administration modalities such as the DBRS and the 24-hr should be less intercorrelated than measures with similar modalities; for example, two questionnaires. Other possible interpretations for the lower convergent validity include different content domains (cognitive vs. behavioral), different temporal intervals, and different presentation formats. Low convergent validity, yet high correlation of both measures with HbA1c support the necessity to either combine the measures or use the measures in tandem for a more thorough representation of disease care.

Incremental Validity (Hypothesis 6)

Incremental validity analyses poses a fairly stringent test of validity in that an outcome must demonstrate additive value beyond other relevant sources of information (Hunsley & Meyer, 2003). Both the DBRS ($\Delta R^2 = .10$; Table 14) and the 24-hr ($\Delta R^2 = .06$; Table 15) added unique variance in HbA1c which demonstrated adequate incremental validity (Hunsley & Meyer, 2003; Sechrest, 1963). Together, both measures account for more variance in HbA1c than either alone. More importantly, only three subscales, Daily Prevention Behaviors (B = .19) of the DBRS and Frequency of Blood Glucose Monitoring (B = .14), and Meal/Snack Frequency (B = .13) of the 24-hr significantly contributed to HbA1c suggesting a more parsimonious assessment measure (See Table 16). This novel, brief combination of subscales may not only demonstrate a comparable association with HbA1c similar to either measure alone, but also may greatly reduce administration time from ~45 to ~5 minutes. It would also provide multi-method data of actual diabetes behaviors via interview and prevention knowledge via self-report, in one brief measure that could prove efficacious for clinical practice.

External validity (Hypothesis 7)

External validity analyses compared the scores of pump and non-pump users on the DBRS and 24-hr to determine their relation to metabolic control, the chosen index of external validity. Overall, youth with insulin pumps and their parents report greater disease care adherence than non-pump users on the DBRS ($r = .51$ - $.79$ and $r = .48$-$.75$ respectively; See Table 17) and the 24-hr (See Table 18 for specific subscale scores) and correspondingly have better HbA1c ($M = 8.5$, $SD = 1.3$) than youth with non-pump conventional regimens ($M = 9.1$, $SD = 1.8$). However, only DBRS non-pump scores displayed moderate external validity with metabolic control, ($R^2 = .08$-18; See Table 21). The scores of pump users on the DBRS were

unrelated to metabolic control (R^2 =.06-09; See Table 22). The recent pump version of the DBRS developed by Iannotti and colleagues (2006) was adapted from the original non-pump measure by McNabb and colleagues (1994). The McNabb et al. (1994) measure focused on adherence to an ideal regimen as defined in the mid-1990's for predominantly non-pump users and conventional insulin regimens. The updated Ianotti et al. (2006) DBRS measure remains relatively similar to the McNabb et al. (1994) original with a few additional questions related to insulin pump use. Based on the insufficient external validity of the DBRS pump version (R^2 =.06-09) the updated pump version does not appear to fully capture the intricacies of pump regimen as it relates to metabolic control. In addition, if a measure is not significantly related to the gold standard of disease care, HbA1c, this greatly impacts the validity and utility of the measure.

In contrast to the DBRS, the 24-hr did not show differences in external validity between pump and non-pump users in association with HbA1c (R^2 =.19-.24 and R^2 =.14-.22 respectively; See Table 22). The 24-hr measure of disease care appears stable regardless of insulin regimen. Although the 24-hr only has one version, it is completed in an interview style which allows flexibility by interviewers to word questions and by parents and youths to describe a typical day regardless of insulin regimen.

Based on its external validity data, the 24-hr disease care measure can be used with equivalent robustness regardless of insulin regimen type. In contrast, external validity suggests the DBRS is more useful in its description of conventional non-pump regimens and their relation to metabolic control than its description of pump regimens. Accordingly, clinicians may choose the 24-hr measure as a disease care indicator with acceptable external validity, whereas, the

DBRS provides a better indicator of disease care related to metabolic control primarily for youth with non-pump regimens.

Diabetes Family Responsibility Questionnaire as a Moderator of the Relations between Age and HbA1c (Hypothesis 8 and 9)

Hypotheses 8 and 9 examined the relation between parent/youth disease care responsibility, age and HbA1c (Hypothesis 8) and the moderating effect of parent/youth shared responsibility on age and HbA1c (Hypothesis 9). Consistent with previous literature (Anderson, Ho, Brackett, Finkelstein & Laffel, 1997) older youth had more disease care responsibility (r = .23-.35) and older age was related to decline in HbA1c (r = .14). However, no relation between HbA1c and decreased parental responsibility was found (r = .02 - .05; Table 23). In addition, parent/youth responsibility did not moderate the relation between age and metabolic control (ΔR^2 = .00-.01; Table 25).

As youth begin the developmental transition into adolescence, parents become less involved in disease care and disease care declines, which results in poorer metabolic control (Anderson, Ho, Brackett, Finkelstein & Laffel, 1997; Wysocki, 1993; Wysocki et al., 1996; Jacobson et al., 1990). Reduced parental involvement likely decreases parent/youth agreement. Although the literature reports decreased parental diabetes responsibility relates to poorer disease care and metabolic control (Anderson, Ho, Brackett, Finkelstein & Laffel, 1997), the present study failed to find a relation between decreased parental responsibility and poorer metabolic control. Level of parent/youth responsibility also failed to moderate the relation between age and metabolic control. Perhaps this latter finding arises from the lack of relation between parent/youth responsibility and HbA1c, possibly due to the study's condensed age range. A smaller age range of 11- to 14-year-olds in the current study probably restricted the range such

that it was not possible to detect a relation in this early adolescent sample. Range restriction can be ruled out in future studies that sample age more broadly. In addition, previous literature only used three response options: all parent responsibility, all youth responsibility or shared responsibility. Although the current study used five response options to create a more specific and accurate picture of parent/youth responsibility, the different scoring method may have impacted the results. Future research is needed on the DFRQ in this age group to further explain this lack of relation.

Summary

Overall a number of unique findings were displayed in the current study. The reliability analyses replicated and added to previous literature which is critical in establishing the legitimacy and usefulness of the measures. Concurrent validity analyses displayed both measures had significant associations with HbA1c. External validity analyses revealed the 24-hr is more flexible for use with all insulin regimens, while the DBRS might be more useful for youth on basal/bolus regimens or multiple daily injections. Although these results could be a critical factor when choosing a disease care measure, to this date, no study has examined the relation with pump status and Hba1c. Significant correlations were found between both parent/youth responsibility and HbA1c and age, with older youth both taking on more responsibility for disease care and displaying poorer HbA1c. Most importantly, incremental and convergent validity analyses revealed both measures provide unique variance in HbA1c. The 24-hr measures actual behaviors; however, clinical utility is limited by lengthy administration and scoring time. The DBRS is briefer, but restricted to complex diabetes behaviors. Overall, both measures are relatively stable and viable for clinical practice and could be beneficial to use in tandem. However, the possibility of a briefer, yet reliable and valid measure is suggested from

incremental validity results that would eliminate the burden of lengthy administration time, and would allow for greater movement towards the "gold standard" of a multi-method, multi-source measure that most accurately portrays disease care.

Limitations/Future Directions

Although multi-method measurement techniques were utilized, not all possible presentation formats were sampled due to practical considerations. More objective sources of disease care adherence such as insulin pumps and blood glucose meters could be used in future studies as the technology becomes more widely available and cost-effective. A second limitation is the lack of reliability data for the DBRS. The current research was conducted in the context of an ongoing longitudinal study and there was no retest data available. Although previous research provided strong evidence of the test-retest reliability of this measure (Iannotti, 2006), future analyses to replicate these findings would provide further evidence for reliability of the DBRS. A third limitation is the use of cross-sectional data and its inability to make causal inferences. Even though causal relations cannot be identified by cross-sectional research, it can provide strong support for associations among variables and to inform future research (Kazdin, 2003). In the future, longitudinal predictive validity would test the ability of measures to predict future HbA1c numbers and would enhance the description of clinical utility.

Interrater reliability, which measures the extent to which different assessors, raters or observers agree on the scores they provide when assessing, coding or classifying subjects' performance (Kazdin, 2003) was not examined in the current study. Although a reliability of .85 was required for the accuracy of data entry of the 24-hr, it could be beneficial to create a more established criterion. Because the 24-hr is open to interpretation during the interview, interrater reliability would allow for a more precise gauge on the accuracy of measurement and increase

refinement. However, the reality of the fast paced nature of clinical research and the time it takes to record and score multiple lengthy interviews, requires more practical and cost-efficient methods. Therefore, in the current study an extremely, detailed coding manual and highly trained assessors were established.

Lastly, the possible creation of a briefer, yet reliable and valid measure exists in the future. Future research combining the subscales of Diabetes Prevention Behavior subscale of the DBRS and Frequency of Blood Glucose Monitoring and Meal/Snack Frequency subscales of the 24-hr into a single multi-method (self-report, interview) and multi-source (parent and youth) measure could prove tremendously useful for future clinical practice.

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Appendix A

Diabetes Behavior Rating Scale (Parent Pump version)

The following questions are about behaviors that either you or your child does to help take care of your child's diabetes. We would like to know how often these behaviors are being done. It does not matter who does them, just how often they are done.

A. DAILY PREVENTION BEHAVIORS

For the following question please think about how often each of the described behaviors was actually done in your family in the last 7 days.

In the last 7 days, how often…	Never[0]	Seldom[1]	About half the time[2]	Usually[3]	Always[4]
1. were meals planned according to the system you use?	∈	∉	∠	∇	®
2. were foods weighed or measured?	∈	∉	∠	∇	®
3. were food labels used for planning meals?	∈	∉	∠	∇	®
4. were fatty foods eaten more than the meal plan allowed or the doctor recommended?	∈	∉	∠	∇	®
5. were sweets eaten more than the meal plan allowed or the doctor recommended?	∈	∉	∠	∇	®
6. was the amount of insulin that the doctor prescribed (including adjustments for diet or blood glucose level) actually taken?	∈	∉	∠	∇	®
7. was insulin taken at the time your child was supposed to?	∈	∉	∠	∇	®
8. was the amount of insulin your child took written in a daily log?	∈	∉	∠	∇	®
9. was the pump inserted and working correctly?	∈	∉	∠	∇	®
10. was the pump site changed at least every three days?	∈	∉	∠	∇	®
11. was the injection site checked for signs of infection (e.g. redness or soreness)?	∈	∉	∠	∇	®
12. were blood sugar levels tested as often as recommended by the doctor?	∈	∉	∠	∇	®
13. was blood sugar checked at the time of the day it should be?	∈	∉	∠	∇	®
14. were blood sugar numbers written in a log, diary, or chart?	∈	∉	∠	∇	®
15. was "fast sugar" (like candy, juice) with your child?	∈	∉	∠	∇	®
16. did your child get exercise or participate in physical activity for at least 20 minutes?	∈	∉	∠	∇	®
17. was a bracelet or necklace that tells people your child has diabetes worn?	∈	∉	∠	∇	®
18. were blood sugar levels tested every time your child ate?	∈	∉	∠	∇	®

B. MODIFICATIONS OF DIABETES CARE PLAN

There are some adjustments that need to be made in diabetes care in certain situations. These may or may not be done on a daily basis. We are interested in knowing how often these behaviors are practiced when called for.

Please think about the last 5 times that the described situation occurred, not just the most recent time. In how many of these times was the described behavior done?

Out of the last 5 times...	None[0]	1 time	2 times	3 times	4 times	5 times
19. that the amount of exercise changed, how often were meals and snacks changed?	⓪	∈	∉	∠	∇	®
20. that the amount of exercise changed, how often was total insulin dose (bolus) changed?	⓪	∈	∉	∠	∇	®
21. that less or more food was eaten than usual, how often was total insulin dose (bolus) changed?	⓪	∈	∉	∠	∇	®
22. that blood sugar levels were higher or lower than usual, how often was the amount of exercise changed?	⓪	∈	∉	∠	∇	®
23. that blood glucose was out of the target range, how often was the total insulin dose (bolus) adjusted?	⓪	∈	∉	∠	∇	®
24. that your child needed help for diabetes in school, home, or social settings, how often was help obtained?	⓪	∈	∉	∠	∇	®

C. INTERVENTION BEHAVIORS

There are also actions that are taken only when your child has symptoms of "low" or "high" blood sugar. Many of these actions are listed below. Please think about the last five times that your child had symptoms, not just the most recent time. How often were the described behaviors practiced then?

Out of the last 5 times when your child had symptoms of being "LOW", how often...	None[0]	1 time	2 times	3 times	4 times	5 times
25. was blood sugar checked?	⓪	∈	∉	∠	∇	®
26. was "fast sugar" (like juice) taken within 10 minutes?	⓪	∈	∉	∠	∇	®
27. was blood sugar checked within 20 minutes after having taken "fast sugar"?	⓪	∈	∉	∠	∇	®
28 was "regular food" eaten after needing to take "fast-sugar"?	⓪	∈	∉	∠	∇	®
29. was too much food eaten so that blood sugar went too high after being low?	⓪	∈	∉	∠	∇	®

Out of the last 5 times when your child had symptoms of being "HIGH", how often…	None[0]	1 time	2 times	3 times	4 times	5 times
30. was blood sugar checked?	⓪	∈	∉	∠	∇	®
31. was insulin dose changed because of the results of blood sugar tests?	⓪	∈	∉	∠	∇	®

D. OTHER DIABETES CARE PRACTICES

There are other important diabetes care behaviors that do not occur very often. Please answer the following questions about these behaviors.

How often…	Never[0]	Seldom[1]	About half the time[2]	Usually[3]	Always[4]
32. is insulin correctly adjusted for meals eaten away from the home (e.g., at restaurants, parties)?	∈	∉	∠	∇	®
33. are your child's friends, teachers, coaches and others told how to treat "low" blood sugar?	∈	∉	∠	∇	®
34. are the school nurse, dentist, and eye doctor told that your child has diabetes?	∈	∉	∠	∇	®
35. are clinic or doctors appointments kept?	∈	∉	∠	∇	®
36. is a doctor/nurse called for changes in insulin dose because of frequent "high" or "low" blood sugar levels?	∈	∉	∠	∇	®
37. is the doctor/nurse called when your child has severe diabetic symptoms (e.g., drinking a lot, needing fast sugar a lot)?	∈	∉	∠	∇	®
[9] *Mark here if your child has never had symptoms you couldn't correct*					

Diabetes Behavior Rating Scale (Youth Pump version)

The following questions are about behaviors that either you or your parents do to help you take care of your diabetes. We would like to know how often these behaviors are being done. We do not care who in your family does the behavior, just how often it is done.

A. DAILY PREVENTION BEHAVIORS

For the following question please think about how often you or your parents have done each of the described behaviors in the last 7 days.

How often	Never[0]	Seldom[1]	About half the time[2]	Usually[3]	**Always[4]**
1. were your meals planned according to the system you use?	∈	∉	∠	∇	®
2. were your foods weighed or measured?	∈	∉	∠	∇	®
3. were food labels used for planning meals?	∈	∉	∠	∇	®
4. were fatty foods eaten more than your meal plan allowed or your doctor recommended?	∈	∉	∠	∇	®
5. were sweets eaten more than your meal plan allowed or your doctor recommended?	∈	∉	∠	∇	®
6. was the amount of insulin that your doctor prescribed (including adjustments for diet or blood glucose level) actually taken?	∈	∉	∠	∇	®
7. was your insulin taken at the time you were supposed to?	∈	∉	∠	∇	®
8. was the amount of insulin you took written in your daily log?	∈	∉	∠	∇	®
9. was the pump inserted and working correctly?	∈	∉	∠	∇	®
10. was the pump site changed at least every three days?	∈	∉	∠	∇	®
11. was the injection site checked for signs of infection (e.g. redness or soreness)?	∈	∉	∠	∇	®
12. were blood sugar levels tested as often as recommended by the doctor?	∈	∉	∠	∇	®
13. was your blood sugar checked at the time of the day it should be?	∈	∉	∠	∇	®
14. were your blood sugar numbers written in your log, diary, or chart?	∈	∉	∠	∇	®
15. was "fast sugar" (like candy, juice) with you?	∈	∉	∠	∇	®
16. did you get exercise or participate in physical activity for at least 20 minutes?	∈	∉	∠	∇	®
17. was a bracelet or necklace that tells people you have diabetes worn?	∈	∉	∠	∇	®
18. were blood sugar levels tested every time you ate?	∈	∉	∠	∇	®

B. MODIFICATIONS OF DIABETES CARE PLAN

There are some adjustments that need to be made in diabetes care in certain situations. These

may or may not be done on a daily basis. We are interested in knowing how often these behaviors are practiced when called for.
Please think about the last 5 times that the described situation occurred, not just the most recent time. In how many of these times was the described behavior done?

Out of the last 5 times…	None⁰	1 time	2 times	3 times	4 times	**5 times**
19. that the amount of exercise you did changed, how often were your meals and snacks changed?	⓪	∈	∉	∠	∇	®
20. that the amount of exercise you did changed, how often was total insulin dose (bolus) changed?	⓪	∈	∉	∠	∇	®
21. that less or more food was eaten than usual, how often was total insulin dose (bolus) changed?	⓪	∈	∉	∠	∇	®
22. that blood sugar levels were higher or lower than usual, how often was the amount of exercise changed?	⓪	∈	∉	∠	∇	®
23. that your blood glucose was out of the target range, how often was your total insulin dose (bolus) adjusted?	⓪	∈	∉	∠	∇	®
24. that you needed help for your diabetes in school, home, or social settings, how often was help obtained?	⓪	∈	∉	∠	∇	®

C. INTERVENTION BEHAVIORS

There are also actions that are taken only when you have symptoms of "low" or "high" blood sugar. Many of these actions are listed below. Please think about the last five times that you had symptoms, not just the most recent time. How often were the described behaviors practiced then?

Out of the last 5 times when you had symptoms of being "LOW", how often…	None⁰	1 time	2 times	3 times	4 times	**5 times**
25. was your blood sugar checked?	⓪	∈	∉	∠	∇	®
26. was "fast sugar" (like juice) taken within 10 minutes?	⓪	∈	∉	∠	∇	®
27. was your blood sugar checked within 20 minutes after having taken "fast sugar"?	⓪	∈	∉	∠	∇	®
28. was "regular food" eaten after needing to take "fast-sugar"?	⓪	∈	∉	∠	∇	®
29. was too much food eaten so that your blood sugar went too high after being low?	⓪	∈	∉	∠	∇	®

Out of the last 5 times when you had symptoms of being "HIGH", how often…	None⁰	1 time	2 times	3 times	4 times	**5 times**
30. was your blood sugar checked?	⓪	∈	∉	∠	∇	®

Out of the last 5 times when you had symptoms of being "HIGH", how often…	None[0]	1 time	2 times	3 times	4 times	**5 times**
31. was insulin dose changed based on the results of a blood sugar test?	⓪	∈	∉	∠	∇	®

F. OTHER DIABETES CARE PRACTICES

There are other important diabetes care behaviors that do not occur very often. Please answer the following questions about these behaviors.

How often…	Never[0]	Seldom[1]	About half the time[2]	Usually[3]	**Always[4]**
32. is insulin correctly adjusted for meals you eat away from the home (e.g., at restaurants, parties)?	∈	∉	∠	∇	®
33. are your friends, teachers, coaches, and others told how to treat "low" blood sugar?	∈	∉	∠	∇	®
34. are your school nurse, dentist, and eye doctor told that you have diabetes?	∈	∉	∠	∇	®
35. are clinic or doctors appointments kept?	∈	∉	∠	∇	®
36. is your doctor/nurse called for changes in insulin dose if you get frequent "high" or "low" blood sugar levels?	∈	∉	∠	∇	®
37. is your doctor/nurse called if you have severe diabetic symptoms that you cannot correct (e.g., drinking a lot, needing fast sugar a lot)?	∈	∉	∠	∇	®
9 *Mark here if you've never had symptoms you couldn't correct*					

Diabetes Behavior Rating Scale (Parent Non-Pump version)

The following questions are about behaviors that either you or your child does to help take care of your child's diabetes. We would like to know how often these behaviors are being done. It does not matter who does them, just how often they are done.

A. DAILY PREVENTION BEHAVIORS

For the following question please think about how often each of the described behaviors was actually done in your family in the last 7 days.

In the last 7 days, how often…	Never[0]	Seldom[1]	About half the time[2]	Usually[3]	Always[4]
1. were meals planned according to the system you use?	∈	∉	∠	∇	®
2. were foods weighed or measured?	∈	∉	∠	∇	®
3. were food labels used for planning meals?	∈	∉	∠	∇	®
4. were fatty foods eaten more than the meal plan allowed or the doctor recommended?	∈	∉	∠	∇	®
5. were sweets eaten more than the meal plan allowed or the doctor recommended?	∈	∉	∠	∇	®
6. was the amount of insulin that the doctor prescribed (including adjustments for diet or blood glucose level) actually taken?	∈	∉	∠	∇	®
7. was insulin taken at the time your child was supposed to?	∈	∉	∠	∇	®
8. was the amount of insulin your child took written in a daily log?	∈	∉	∠	∇	®
9. were insulin shots given correctly?	∈	∉	∠	∇	®
10. were insulin shots given in different parts of the body?	∈	∉	∠	∇	®
11. were blood sugar levels tested as often as recommended by the doctor?	∈	∉	∠	∇	®
12. was blood sugar checked at the time of the day it should be?	∈	∉	∠	∇	®
13. were blood sugar numbers written in a log, diary, or chart?	∈	∉	∠	∇	®
14. was "fast sugar" (like candy, juice) with your child?	∈	∉	∠	∇	®
15. did your child get exercise or participate in physical activity for at least 20 minutes?	∈	∉	∠	∇	®
16. was a bracelet or necklace that tells people your child has diabetes worn?	∈	∉	∠	∇	®
17. were blood sugar levels tested every time your child ate?	∈	∉	∠	∇	®

B. MODIFICATIONS OF DIABETES CARE PLAN

There are some adjustments that need to be made in diabetes care in certain situations. These may or may not be done on a daily basis. We are interested in knowing how often these behaviors are practiced when called for.

Please think about the last 5 times that the described situation occurred, not just the most recent time. In how many of these times was the described behavior done?

Out of the last 5 times…	None⁰	1 time	2 times	3 times	4 times	5 times
18. that the amount of exercise changed, how often were meals and snacks changed?	⓪	∈	∉	∠	∇	®
19. that the amount of exercise changed, how often was total insulin dose changed?	⓪	∈	∉	∠	∇	®
20. that less or more food was eaten than usual, how often was total insulin dose changed?	⓪	∈	∉	∠	∇	®
21. that blood sugar levels were higher or lower than usual, how often was the amount of exercise changed?	⓪	∈	∉	∠	∇	®
22. that blood glucose was out of the target range, how often was the total insulin dose adjusted?	⓪	∈	∉	∠	∇	®
23. that your child needed help for diabetes in school, home, or social settings, how often was help obtained?	⓪	∈	∉	∠	∇	®

C. INTERVENTION BEHAVIORS

There are also actions that are taken only when your child has symptoms of "low" or "high" blood sugar. Many of these actions are listed below. Please think about the last five times that your child had symptoms, not just the most recent time. How often were the described behaviors practiced then?

Out of the last 5 times when your child had symptoms of being "LOW", how often…	None⁰	1 time	2 times	3 times	4 times	5 times
24. was blood sugar checked?	⓪	∈	∉	∠	∇	®
25. was "fast sugar" (like juice) taken within 10 minutes?	⓪	∈	∉	∠	∇	®
26. was blood sugar checked within 20 minutes after having taken "fast sugar"?	⓪	∈	∉	∠	∇	®
27. was "regular food" eaten after needing to take "fast-sugar"?	⓪	∈	∉	∠	∇	®
28. was too much food eaten so that blood sugar went too high after being low?	⓪	∈	∉	∠	∇	®

Out of the last 5 times when your child had symptoms of being "HIGH", how often…	None⁰	1 time	2 times	3 times	4 times	5 times
29. was blood sugar checked?	⓪	∈	∉	∠	∇	®
30. was insulin dose changed because of the results of blood sugar tests?	⓪	∈	∉	∠	∇	®

D. OTHER DIABETES CARE PRACTICES

There are other important diabetes care behaviors that do not occur very often. Please answer the following questions about these behaviors.

How often…	Never[0]	Seldom[1]	About half the time[2]	Usually[3]	Always[4]
31. is insulin correctly adjusted for meals eaten away from the home (e.g., at restaurants, parties)?	∈	∉	∠	∇	®
32. are your child's friends, teachers, coaches and others told how to treat "low" blood sugar?	∈	∉	∠	∇	®
33. are the school nurse, dentist, and eye doctor told that your child has diabetes?	∈	∉	∠	∇	®
34. are clinic or doctors appointments kept?	∈	∉	∠	∇	®
35. is a doctor/nurse called for changes in insulin dose because of frequent "high" or "low" blood sugar levels?	∈	∉	∠	∇	®
36. is the doctor/nurse called when your child has severe diabetic symptoms (e.g., drinking a lot, needing fast sugar a lot)?	∈	∉	∠	∇	®
9 *Mark here if your child has never had symptoms you couldn't correct*					

Diabetes Behavior Rating Scale (Youth Non-Pump version)

The following questions are about behaviors that either you or your parents do to help you take care of your diabetes. We would like to know how often these behaviors are being done. We do not care who in your family does the behavior, just how often it is done.

A. DAILY PREVENTION BEHAVIORS

For the following question please think about how often you or your parents have done each of the described behaviors in the last 7 days.

How often	Never[0]	Seldom[1]	About half the time[2]	Usually[3]	**Always[4]**
1. were your meals planned according to the system you use?	∈	∉	∠	∇	®
2. were your foods weighed or measured?	∈	∉	∠	∇	®
3. were food labels used for planning meals?	∈	∉	∠	∇	®
4. were fatty foods eaten more than your meal plan allowed or your doctor recommended?	∈	∉	∠	∇	®
5. were sweets eaten more than your meal plan allowed or your doctor recommended?	∈	∉	∠	∇	®
6. was the amount of insulin that your doctor prescribed (including adjustments for diet or blood glucose level) actually taken?	∈	∉	∠	∇	®
7. was your insulin taken at the time you were supposed to?	∈	∉	∠	∇	®
8. was the amount of insulin you took written in your daily log?	∈	∉	∠	∇	®
9. were your insulin shots given correctly?	∈	∉	∠	∇	®
10. were your insulin shots given in different parts of your body?	∈	∉	∠	∇	®
11. were blood sugar levels tested as often as recommended by the doctor?	∈	∉	∠	∇	®
12. was your blood sugar checked at the time of the day it should be?	∈	∉	∠	∇	®
13. were your blood sugar numbers written in your log, diary, or chart?	∈	∉	∠	∇	®
14. was "fast sugar" (like candy, juice) with you?	∈	∉	∠	∇	®
15. did you get exercise or participate in physical activity for at least 20 minutes?	∈	∉	∠	∇	®
16. was a bracelet or necklace that tells people you have diabetes worn?	∈	∉	∠	∇	®
17. were blood sugar levels tested every time you ate?	∈	∉	∠	∇	®

B. MODIFICATIONS OF DIABETES CARE PLAN

There are some adjustments that need to be made in diabetes care in certain situations. These may or may not be done on a daily basis. We are interested in knowing how often these behaviors are practiced when called for.

Please think about the last 5 times that the described situation occurred, not just the most recent time. In how many of these times was the described behavior done?

Out of the last 5 times...	0 None	1 time	2 times	3 times	4 times	**5 times**
18. that the amount of exercise you did changed, how often were your meals and snacks changed?	⓪	∈	∉	∠	∇	®
19. that the amount of exercise you did changed, how often was total insulin dose changed?	⓪	∈	∉	∠	∇	®
20. that less or more food was eaten than usual, how often was total insulin dose changed?	⓪	∈	∉	∠	∇	®
21. that blood sugar levels were higher or lower than usual, how often was the amount of exercise changed?	⓪	∈	∉	∠	∇	®
22. that your blood glucose was out of the target range, how often was your insulin dose adjusted?	⓪	∈	∉	∠	∇	®
23. that you needed help for your diabetes in school, home, or social settings, how often was help obtained?	⓪	∈	∉	∠	∇	®

C. INTERVENTION BEHAVIORS

There are also actions that are taken only when you have symptoms of "low" or "high" blood sugar. Many of these actions are listed below. Please think about the last five times that you had symptoms. How often were the described behaviors practiced then?

Out of the last 5 times when you had symptoms of being "low", how often...	0 None	1 time	2 times	3 times	4 times	**5 times**
24. was your blood sugar checked?	⓪	∈	∉	∠	∇	®
25. was "fast sugar" (like juice) taken within 10 minutes?	⓪	∈	∉	∠	∇	®
26. was your blood sugar checked within 20 minutes after having taken "fast sugar"?	⓪	∈	∉	∠	∇	®
27. was "regular food" eaten after needing to take "fast-sugar"?	⓪	∈	∉	∠	∇	®
28. was too much food eaten so that your blood sugar went too high after being low?	⓪	∈	∉	∠	∇	®

Out of the last 5 times when you had symptoms of being "HIGH", how often...	None[0]	1 time	2 times	3 times	4 times	**5 times**
29. was your blood sugar checked?	⓪	∈	∉	∠	∇	®

Out of the last 5 times when you had symptoms of being "HIGH", how often…	None[0]	1 time	2 times	3 times	4 times	**5 times**
30. was insulin dose changed based on the results of a blood sugar test?	⓪	∈	∉	∠	∇	®

D. OTHER DIABETES CARE PRACTICES

There are other important diabetes care behaviors that do not occur very often. Please answer the following questions about these behaviors.

How often…	Never[0]	Seldom[1]	About half the time[2]	Usually[3]	**Always[4]**
31. is insulin correctly adjusted for meals you eat away from the home (e.g., at restaurants, parties)?	∈	∉	∠	∇	®
32. are your friends, teachers, coaches, and others told how to treat "low" blood sugar?	∈	∉	∠	∇	®
33. are your school nurse, dentist, and eye doctor told that you have diabetes?	∈	∉	∠	∇	®
34. are clinic or doctors appointments kept?	∈	∉	∠	∇	®
35. is your doctor/nurse called for changes in insulin dose if you get frequent "high" or "low" blood sugar levels?	∈	∉	∠	∇	®
36. is your doctor/nurse called if you have severe diabetic symptoms that you cannot correct (e.g., drinking a lot, needing fast sugar a lot)?	∈	∉	∠	∇	®
9 *Mark here if you've never had symptoms you couldn't correct*					

Appendix B

DECIDE 24 – Hour Recall Interview *Was this day typical* (eating, stress, exercise, illness)? Yes ( ) No ( ) If No, Why?_____

NOTES Record extra snacks, injections, BG checks on back, and circle

Patient's Name_____ Subject #_____ T____ Today's Date:_____ For Weekday ( ) or Weekend ( )

DOB_____ Parent ( ) or Child ( ) Interview Interviewer's Initials_____ Coding sheet Initials_____

How Many Shots Does Child Usually Recieve: 1 2 3 4 5 6 CSII Pump

Type of Regimen: Pump[1], Lantus[2], Regular + NPH[3] Do you use carbohydrate/insulin ratios to determine insulin doses? Yes[1] No[0]

BG CHECKS:

#1Time AM/PM	#2Time AM/PM	#3Time AM/PM	#4Time AM/PM
BG Level _____	BG Level _____	BG Level _____	BG Level _____
Who?: Child Mother Father Other	Who?: Child Mother Father Other	Who?: Child Mother Father Other	Who?: Child Mother Father Other
If child, Adult Observe? Yes ( ) No ( )	If child, Adult Observe? Yes ( ) No ( )	If child, Adult Observe? Yes ( ) No ( )	If child, Adult Observe? Yes ( ) No ( )
Did you discuss? Yes ( ) No ( )	Did you discuss? Yes ( ) No ( )	Did you discuss? Yes ( ) No ( )	Did you discuss? Yes ( ) No ( )
Did anything if ≤70 or ≥200? Yes ( ) No ( )	Did anything if ≤70 or ≥200? Yes ( ) No ( )	Did anything if ≤70 or ≥200? Yes ( ) No ( )	Did anything if ≤70 or ≥200? Yes( ) No( )
If Yes, what? _____	If Yes, what? _____	If Yes, what? _____	If Yes, what? _____

#5Time AM/PM	#6Time AM/PM	#7Time AM/PM	#8Time AM/PM
BG Level _____	BG Level _____	BG Level _____	BG Level _____
Who?: Child Mother Father Other	Who?: Child Mother Father Other	Who?: Child Mother Father Other	Who?: Child Mother Father Other
If child, Adult Observe? Yes ( ) No ( )	If child, Adult Observe? Yes ( ) No ( )	If child, Adult Observe? Yes ( ) No ( )	If child, Adult Observe? Yes ( ) No ( )
Did you discuss? Yes ( ) No ( )	Did you discuss? Yes ( ) No ( )	Did you discuss? Yes ( ) No ( )	Did you discuss? Yes ( ) No ( )
Did anything if ≤70 or ≥200? Yes ( ) No ( )	Did anything if ≤70 or ≥200? Yes ( ) No ( )	Did anything if ≤70 or ≥200? Yes ( ) No ( )	Did anything if ≤70 or ≥200? Yes( ) No( )
If Yes, what? _____	If Yes, what? _____	If Yes, what? _____	If Yes, what? _____

INSULIN INJECTIONS/BOLUSES

#1Time AM/PM	#2Time AM/PM	#3Time AM/PM	#4Time AM/PM
Who gave shot? Child Mother Father Other_____	Who gave shot? Child Mother Father Other_____	Who gave shot? Child Mother Father Other_____	Who gave shot? Child Mother Father Other_____
If child, Adult Observe? Yes ( ) No ( )	If child, Adult Observe? Yes ( ) No ( )	If child, Adult Observe? Yes ( ) No ( )	If child, Adult Observe? Yes ( ) No ( )
Did you discuss? Y( ) N ( )	Did you discuss? Y( ) N ( )	Did you discuss? Y( ) N ( )	Did you discuss? Y( ) N ( )

#5Time AM/PM	#6Time AM/PM	#7Time AM/PM	#8Time AM/PM
Who gave shot? Child Mother Father Other_____	Who gave shot? Child Mother Father Other_____	Who gave shot? Child Mother Father Other_____	Who gave shot? Child Mother Father Other_____
If child, Adult Observe? Yes ( ) No ( )	If child, Adult Observe? Yes ( ) No ( )	If child, Adult Observe? Yes ( ) No ( )	If child, Adult Observe? Yes ( ) No ( )
Did you discuss? Y( ) N ( )	Did you discuss? Y( ) N ( )	Did you discuss? Y( ) N ( )	Did you discuss? Y( ) N ( )

FOOD INTAKE:#1BREAKFAST Time AM/PM	#2SNACK Time AM/PM	#3LUNCH Time AM/PM
Qnty Item	Qnty Item	Qnty Item
_____ _____	_____ _____	_____ _____
_____ _____	_____ _____	_____ _____
_____ _____	_____ _____	_____ _____
_____ _____	_____ _____	_____ _____
_____ _____	_____ _____	_____ _____
_____ _____	_____ _____	_____ _____
_____ _____	_____ _____	_____ _____
_____ _____	_____ _____	_____ _____
_____ _____	_____ _____	_____ _____
_____ _____	_____ _____	_____ _____
Adult Observe? Yes ( ) No ( ) Discuss Y ( ) N ( )	Adult Observe? Yes ( ) No ( ) Discuss Y ( ) N ( )	Adult Observe? Yes ( ) No ( ) Discuss Y ( ) N ( )

#4SNACK Time AM/PM	#5DINNER Time AM/PM	#6 BEDTIME SNACK Time AM/PM
Qnty Item	Qnty Item	Qnty Item
_____ _____	_____ _____	_____ _____
_____ _____	_____ _____	_____ _____
_____ _____	_____ _____	_____ _____
_____ _____	_____ _____	_____ _____
_____ _____	_____ _____	_____ _____
_____ _____	_____ _____	_____ _____
_____ _____	_____ _____	_____ _____
_____ _____	_____ _____	_____ _____
_____ _____	_____ _____	_____ _____
_____ _____	_____ _____	_____ _____
Adult Observe? Yes ( ) No ( ) Discuss Y ( ) N ( )	Adult Observe? Yes ( ) No ( ) Discuss Y ( ) N ( )	Adult Observe? Yes ( ) No ( ) Discuss Y ( ) N ( )

EXERCISE:#1Time AM/PM	#2Time AM/PM	#3Time AM/PM
Minutes Activities	Minutes Activities	Minutes Activities
_____ _____	_____ _____	_____ _____
_____ _____	_____ _____	_____ _____
Mild[1] Moderate[2] Strenuous[3]	Mild[1] Moderate[2] Strenuous[3]	Mild[1] Moderate[2] Strenuous[3]
Adult Observe? Yes ( ) No ( ) Discuss Y ( ) N ( )	Adult Observe? Yes ( ) No ( ) Discuss Y ( ) N ( )	Adult Observe? Yes ( ) No ( ) Discuss Y ( ) N ( )

Vita

Kathryn Elizabeth Maher was born on October 31, 1984, in Long Beach California, and is an American citizen. She graduated from Saint Vincent's Academy in Savannah, GA in 2003. She received her Bachelor of Science in Psychology from Mercer University in Macon, GA. She served as a research assistant for the Diabetes Adolescent Research team one year prior to starting the Doctoral program at Virginia Commonwealth University.