Development of the Diabetes Family Adherence Measure (D–FAM)

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The objective of this research was to develop and validate the Diabetes Family Adherence Measure (D–FAM), a comprehensive and up-to-date tool designed for the assessment of adherence-related parenting behaviors for youth with type 1 diabetes (T1D). Further, this article outlines an empirical approach for scale design. First, experts reviewed a battery of potential items to create a preliminary version of the D–FAM. Subsequently, 165 youth with T1D and their families completed an initial administration. A parsimonious measure resulted, consisting of 19 items with 4 additional validity items. Factor analysis identified supportive, coercive, control, and monitoring subscales. D–FAM factors were generally associated with both adherence and health status (HbA1c [glycosolated hemoglobin]), as well as with extant scales of family functioning. Strong internal consistency, test–retest reliability, and construct-convergent reliability were obtained. This initial evaluation of the D–FAM suggests utility for efficient evaluation of family functioning related to adherence and glycemic control for research and clinical purposes.

Improperly managed type 1 diabetes (T1D), a relatively common disease of childhood, is associated with significant morbidity and mortality (Diabetes Control and Complication Trial, 1993). Despite the advent of intensive treatment regimens that can help minimize the risk of life-threatening complications, parents and their children struggle to implement medical recommendations. Although many factors relate to suboptimal adherence (Johnson, 1994), experts have identified family dynamics to be a critical but understudied variable in understanding the optimization of adherence behaviors (La Greca & Mackey, 2009; Rapoff, 1999).

Researchers have established links between several aspects of family functioning and both regimen adherence and health status indicators (e.g., metabolic control; Hood, Butler, Anderson, & Laffel, 2007; McKelvey et al., 1993; Miller-Johnson et al., 1994). For example, positive parental emotional support (e.g., expressing understanding regarding the difficulties of living with diabetes and the treatment regimen and relating to their child about having diabetes) has been associated with improved metabolic control (Lewin, Geffken, et al., 2005; Lewin et al., 2006; McKelvey et al., 1993; McKelvey et al., 1989). La Greca et al. (1995) found that diabetes-related parental supportive behaviors related to adherence with all major components of the diabetes care regimen (e.g., insulin administration, testing, and diet). Data from a longitudinal study also supports an association between family communication and improved metabolic control (Jacobson et al., 1990, 1994).

In addition, sufficient (but non-coercive) parental guidance with diabetes-related care tasks is positively correlated with improved diabetes health status indicators, such as metabolic control (Lewin, Geffken, et al., 2005; McKelvey et al., 1993; Waller et al., 1986). Studies have also found that patients experiencing high levels of family conflict display poorer adherence or worse
metabolic control (La Greca & Mackey, 2009; Miller-Johnson et al., 1994). More specifically, negative and unsupportive parental behavior patterns related to diabetes care behaviors (e.g., coercion, nagging, threats, criticism, and scolding) are correlated with both metabolic control and regimen adherence (Lewin et al., 2006; Schafer, Glasgow, McCaul, & Dreher, 1983; Schafer, McCaul, & Glasgow, 1986). Further, in a study evaluating a parent-adolescent teamwork approach to diabetes management, families in the intervention group reported significantly less parent–child conflict related to diabetes management and were in better metabolic control (Anderson, Brackett, Ho, & Laffel, 1999). Overall, family conflict specific to diabetes care has been the factor most strongly related to both metabolic control (Lewin, Geffken, et al., 2005; Lewin et al., 2006) and diabetic ketoacidosis (DKA; Geffken et al., 2008).

Appropriate parental supervision of diabetes care tasks is also related to adherence and health status. Wysocki et al. (1996) also examined families’ diabetes responsibility relative to the child’s developmental level. Results indicated that children reporting more diabetes management responsibilities demonstrated less adherence and worse metabolic control. Parents who are less involved have children who are less adherent with their treatment regimen, have children who make more mistakes in self-care, and have poorer metabolic control than children whose parents are involved in a developmentally appropriate style (Weissberg-Benchell et al., 1995; Wysocki et al., 1996). More recently, a study of 127 adolescents found that maternal un-involvement with a child’s treatment regimen was associated with poorer adherence and worse quality of life (Wiebe et al., 2005). Anderson, Auslander, Jung, Miller, and Santiago (1990) found that disagreements between parents and children regarding responsibility for diabetes-related tasks predicted poor metabolic control. In addition, these researchers found that poorer metabolic control was positively correlated with families in which neither the parent nor child assumed responsibility for diabetes-related tasks.

Consistent with the extant literature, studies have found that parental involvement was important across all ages (with regard to maximizing adherence), although the optimal level of involvement varies with age and developmental level (Anderson, Ho, Brackett, Finkelstein, & Laffel, 1997; Anderson & Laffel, 1997). One major challenge is matching the child’s emerging developmental desire for independence with appropriate parental supervision for disease-related tasks. Research suggests that in a T1D regimen, nonadherence peaks during middle adolescence (Kovacs, Goldston, Obrosky, & Iyengar, 1992). Indeed, some evidence suggests that non-adherence may arise due to inappropriate transfer of disease-related control from parent to adolescent (Gowers, Jones, Kiana, North, & Price, 1995). Moreover, parents must gauge how to turn over responsibility to the adolescent during this transition. Although there is agreement in the literature that shifts of responsibility should be gradual, adolescents and
parents are likely to approach the transferring of responsibility from differ-
ent perspectives (Dashiff, Bartolucci, Wallander, & Abdullatif, 2005). Because
adolescents desire more freedom and autonomy, whereas parents prefer more
conventional perspectives related to compliance, these differing perspectives can
result in diabetes-related parent–child conflict (Dashiff et al., 2005). Overall,
better adherence has been documented when parents were seen as collaborating,
not controlling, when dealing with their adolescent’s diabetes-related problems
(Wiebe et al., 2005).

Overall, these findings linking metabolic control to diabetes-specific family
processes (such as parental involvement in diabetes tasks and the child’s
perception of the valence of diabetes-related parental behaviors and support)
highlight the importance of these constructs. Anderson and Laffel (1997) de-
scribed diabetes-specific family functioning as critical constructs for assessment
in order to optimize metabolic control and adherence outcomes. Although
relations between individual family processes (e.g., responsibility, parental
warmth, etc.) with metabolic control are relatively small, experts suggest that
incorporating multiple diabetes-related family constructs might demonstrate a
stronger connection with metabolic control (Lewin et al., 2006; McKelvey et al.,
1993).

Despite these findings, relations of each individual family process (e.g.,
responsibility, parental warmth, etc.) with glycemic control and adherence are
relatively small (partial correlations between .12–.32; Anderson et al., 1990;
Schafer et al., 1986; Waller et al., 1986). However, recent multivariate analysis
suggested the utility of assessing multiple domains of diabetes-specific family
functioning simultaneously. Specifically, as much as 49% of the variance in
glycemic control (Duke et al., 2008; Lewin et al., 2006) and 44% of the variance
in DKA (Geffken et al., 2008) can be accounted for by assessing multiple
diabetes related parenting and family behaviors.

Nevertheless, there are limitations to simultaneous assessment of multiple
family factors, as described earlier. First, despite the use of multiple rating scales,
no empirical procedures (e.g., factor analysis) were implemented to determine if
the combined battery assessed multiple aspects of family functioning. Second,
researchers (and clinicians) are limited by the absence of a validated instrument
designed to assess multiple domains of diabetes-specific family functioning
simultaneously. Third, the technology of a diabetes treatment regimen has in-
creased exponentially over the past 2 decades (since the advent of many of
the extant measures of family functioning). Consequently, these measures may
(a) not adequately assess recent complexities of the care regimen that place
increased demands on families (e.g., carbohydrate counting and intensive insulin
therapy or pumps); or alternatively, (b) language of extant measures may not
be robust enough to be applicable to the wide range of current regimens (e.g.,
referring to mixing insulin, delaying meals, rolling vials, and other behaviors that may not be required for newer regimens).

The objective of this research was to develop and validate the Diabetes Family Adherence Measure (D–FAM), an up-to-date, comprehensive, youth-rated measure of diabetes-related parenting and family processes for youth with T1D. This measure was designed to provide a tool for clinicians and researchers to efficiently assess multiple family behaviors that (a) correspond with adherence to the diabetes treatment regimen and (b) have been linked to diabetes-related health status (e.g., HbA1c [glycosolated hemoglobin] and DKA). This study examined the psychometric properties including factor structure, reliability, and validity of the D–FAM.

METHOD

Phase 1: Item Generation and Selection

Initial items (100) were generated by Adam B. Lewin based on family-functioning constructs associated with adherence and glycemic control in the extant literature (e.g., support, conflict or coercion, guidance, and responsibility). Items were presented on a 5-point ordinal frequency scale ranging from 1 (never) to 5 (always). One half of the items were negatively phrased to discourage response sets (Comrey, 1988). Scoring was later reversed on these items for consistency. Subsequently, a panel of 20 experts from eight university-based medical centers (7 endocrinologists, 6 certified diabetes nurse educators, and 7 psychologists with expertise in pediatric diabetes) reviewed items for their appropriateness. Each member of the panel was provided with all 100 initial items. Raters were asked to mark preliminarily D–FAM items that appeared appropriate, irrelevant–inapplicable, confusing–poorly worded, and to suggest areas of missing content. The panel was also given an opportunity to (a) suggest edits to response choices and (b) evaluate the appropriateness of validity items (i.e., raters were asked to list the 5 most appropriate items). Based on expert feedback, the D–FAM was reduced to 70 items. Retention of items was conservative—items that were marked as confusing or inapplicable by 1 or more panel members were deleted. Further, only items that were marked as appropriate by at least 85% of the panel were retained, although the content of several items (approximately 20%) was modified based on expert feedback. Eight validity items, designed to assess careful responding and desire to appear favorably, were selected based on panel ratings. Subsequently, the order of the questions was randomized, and 5 panel members were asked to reevaluate the D–FAM prior to Phase 2.
Phase 2: Measure Evaluation

Participants and Procedures

A total of 165 pediatric patients with T1D (ages 8–18 years)\(^1\) and their primary caregivers were recruited from the university-based pediatric endocrinology clinic in the Southeastern United States. Inclusion criteria were as follows: (a) ages 8 to 18 years, (b) a diagnosis of T1D for at least 1 year, (c) accompanied by a primary caregiver, (d) ability to read and comprehend study materials, and (e) no evidence of developmental disabilities or psychosis (assessed via a screening questionnaire with the parent and clinician observation; confirmed with review of the medical record following receipt of informed consent). Signed informed consent was obtained from each participant. Families were compensated $10 for their participation. The participation rate was 92%. The modal indication for non-participation was time restriction; most of these families agreed to participate at a future appointment. The sample consisted of 68 boys and 97 girls, ages 8 to 18 years (\(M = 13.50\) years, \(SD = 3.00\) years). The ethnic distribution was 70% Caucasian, 17% African American, 11% Hispanic, and 2% representing “other” ethnic groups. Youth participating in this study were predominantly from two-parent families (65.80%), and mothers (76.40%) primarily completed the parent measures. On average, participants had been diagnosed with diabetes for 4.80 years (\(SD = 3.70\); range = 0.5–18 years). On average, sample participants had a mean HbA1c of 8.90 (\(SD = 1.90\); range = 5.00–14.00) and 1.30 episodes of DKA (\(SD = 1.80\); range = 0–8; obtained by parent report).

Experimental Measure

\(D–FAM\). At the time of administration, a youth-rated 70-item (5-point Likert scale) comprehensive measure of T1D adherence-related parenting and family processes (under development and evaluation in this study) was administered. Instructions requested that youth rate items based on the past 3 months, consistent with the HbA1c measurement.

Extant Family Measures

The following diabetes family functioning surveys were selected given their strong association with adherence and health status in previous research (e.g.,

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\(^1\)Please note that subsets of these participants may have been included in the following studies: Duke et al. (2008); Lehmkuhl et al. (2009); Lewin, La Greca, et al. (2009); and Lewin, Storch, et al. (2009). Although participants differ in each of the studies, adherence-metabolic control-family factor relations across studies may reflect some overlap in participants and should not be considered completely independent findings. However, the Diabetes Family Adherence Measure data are isolated to this research article.
Anderson et al., 1997; Lewin, Geffken, et al., 2005; Lewin et al., 2006; McKelvey et al., 1993; Schafer et al., 1986; Waller et al., 1986).

**Diabetes Family Behavior Scale (DFBS; Waller et al., 1986).** The DFBS is a measure of perceived family support completed by youth with T1D. Only the 15-item warmth/caring (WC; e.g., “My parent understands how I feel about having diabetes”) and guidance/control (GC; e.g., “My parent reminds me to test my blood sugar”) subscales were used due to the aims of this study. Participants responded to statements on a 5-point scale ranging from 1 (*all of the time*) to 5 (*never*). Higher scores suggest greater WC or GC. Internal consistency was acceptable with our sample: $\alpha = 0.69$ and 0.71 for the WC and GC subscales, respectively.

**Diabetes Family Behavior Checklist (DFBC; Schafer et al., 1986).** The DFBC is a child-rated measure of family support specific to diabetes. For this research, only the seven-item non-supportive family behavior scale was used. Children rated their parents on items such as, how do your parents “nag you about following your diet.” Items are scored on a 5-point Likert scale ranging from 1 (*never*) to 5 (*at least once a day*). Higher scores suggest more negative and coercive parental behaviors. Good internal consistency ($\alpha = -0.79$) and parent–child agreement ($r = .53$, $p < .001$) have been demonstrated with this scale in previous clinical samples (Lewin, Geffken, et al., 2005). Internal consistency ($\alpha = 0.70$) was acceptable for our sample.

**Diabetes Family Responsibility Questionnaire (DFRQ; Anderson et al., 1990).** The DFRQ assesses the family sharing of responsibilities concerning diabetes treatment. Both the parent and child completed this measure individually by reading a list of 17 diabetes care tasks and indicating which family member accepts responsibility for that specific task (i.e., parent, child, or shared). A parent–child dyadic no-responsibility score is calculated based on patterns of agreement and disagreement within the pair. Higher no-responsibility scores suggest that less responsibility is assumed by either the parent or the child. Acceptable internal consistency ($\alpha = 0.79$) was obtained with this sample.

**Measures of Adherence and Health Status**

**Diabetes Self-Management Profile (DSMP; Harris et al., 2000).** The DSMP is a 23-item structured interview with an administration time of approximately 15 min. Questions assess insulin administration and dose adjustment,
blood-glucose monitoring, exercise, diet, and management of hypoglycemia. Strong parent–child agreement ($r = .56$) and validity (correlation with HbA1c, $r = .60$) have been demonstrated (Lewin, Storch, et al., 2005). Items were responded to in an open-ended manner, and interviews were conducted by study authors (each with over 5 years experience using the DSMP). All items summed to produce a total adherence score; higher scores suggest greater adherence. Acceptable internal consistency was found for both parent ($\alpha = 0.76$) and youth ($\alpha = 0.74$) administrations in our sample. The DSMP was selected given its strong psychometrics (Harris et al., 2000; Iannotti et al., 2006; Lewin, Storch, et al., 2005; Lewin, Storch, et al., 2009), structured-interview format, parallel parent and child versions, and applicability to multiple regimen types (Diabetes Research in Children Network, 2005).

**Measurement of glycemic control.** HbA1c provides a single-measure estimate of glycemic control over the previous 2 to 3 months (American Diabetes Association, 2005) and is considered the gold-standard assay of diabetes metabolic control (Silverstein et al., 2005). Blood samples were analyzed using a Bayer DCA 2000+ (calibrated daily, manufactured by Siemens, Elkhart, IN) and were collected during the study visit when the D–FAM and other measures were completed (as part of the patient’s routine medical care).

**DKA.** Frequency of DKA was obtained by retrospective parental report of lifetime episodes.

**Data Analysis**

Exploratory factor analysis (EFA) was used for scale identification. Principal axis EFA with promax rotation was performed to determine the optimal factor structure of the D–FAM (youth and parent forms separately). The oblique rotation was implemented to allow potential factors to correlate. Criteria for identifying the factors were based on (a) Glorfeld’s (1995) version of parallel analysis, (b) the minimum average partials (MAP) method (Glorfeld, 1995; Velicer, 1976); and (c) the scree plot. A minimum loading of 0.40 was required for each item; items cross-loading ≥ 0.40 on multiple factors would be omitted. Given the ordinal nature of the D–FAM, Spearman’s correlations were used in analyses; $p$ values less than .05 were interpreted. The internal consistency of the D–FAM scores was evaluated using Cronbach’s alpha coefficient (Cronbach, 1951). Hierarchical regression was used for incremental validity and multivariate analysis of variance (MANOVA) for identifying differences in sample characteristics between the test–retest group and the overall sample.
RESULTS

Scale Refinement

Although the D–FAM questionnaire administered to this study sample was initially 70 items, initially, eight questions were designed as potential validity or social desirability indicators (Strahan & Gerbasi, 1972) and were excluded from factor analytical procedures. The majority of the remaining items included multiple phrasing of similar content. Often, three to four times the number of questions that will be included in the final measure are administered to the initial sample (Worthington & Whittaker, 2006). Several considerations were included in eliminating items, such as redundancy, insufficient variation in responses, item-to-total correlations, item means, and inclusion of reverse-scored items (Clark & Watson, 1995; Comrey, 1988; DeVellis, 2003; Worthington & Whittaker, 2006).

Factor Analysis

A principal component EFA with promax rotation was performed to determine the optimal factor structure for this sample. Criteria for identifying the factors were based on (a) Glorfeld’s (1995) version of parallel analysis with a sample size of $N = 165$ and $k = 18$ variables (eigenvalues must be > 5.00 eigenvalues for the first component, 2.50 for the second component, 1.30 for the third component, and 1.00 for the fourth component using the 95th percentile and 1,000 replications), (b) the MAP method (Velicer, 1976), and (c) the scree plot. Syntax for Velicer’s MAP test (O’Connor, 2000) indicated four components. EFA identified a four-factor solution accounting for 63% of the variance (eigenvalues were 5.10, 2.50, 1.40, and 1.30) and was consistent with the scree plot. Data are presented in Table 1. The first factor (7 items), identified as coercion, produced factor loadings that ranged from .489 to .759 (with only 2 values < .5). The second factor contained five items, and was labeled supportive. High factor loadings were obtained, ranging from .537 to .832. The third factor contained three items that can be described as control; factor loadings were high, ranging from .722 to .810. The final factor, labeled monitoring, contained four items. Loadings were also high for this factor, ranging from .617 to .808 (Floyd & Widaman, 1995). Communalities are strong for this model (.2–.4 are adequate; .6 or higher are excellent; MacCallum, Widaman, Zhang, & Hong, 1999).

Internal Consistency

Strong internal consistency was found for each subscale: supportive (0.85), coercive (0.82), monitoring (0.78), and control (0.75). Within-scale inter-item correlations range as follows: supportive (0.46–0.76), coercive (0.37–0.80), monitoring (0.31–0.83), and control (0.33–0.84); $p < .001$ for all values.
## TABLE 1
Rotated Factor Loadings and Initial Communality Coefficients for D–FAM

<table>
<thead>
<tr>
<th>D–FAM Items</th>
<th>Coercion</th>
<th>Supportive</th>
<th>Monitoring</th>
<th>Control</th>
<th>Communalities</th>
</tr>
</thead>
<tbody>
<tr>
<td>My parents blame me when my blood sugar is too high</td>
<td>.707</td>
<td>.260</td>
<td>-.014</td>
<td>.058</td>
<td>.553</td>
</tr>
<tr>
<td>I get yelled at if I forget my insulin</td>
<td>.675</td>
<td>.237</td>
<td>.113</td>
<td>.204</td>
<td>.460</td>
</tr>
<tr>
<td>My parents and I argue because of diabetes</td>
<td>.703</td>
<td>.202</td>
<td>.206</td>
<td>.191</td>
<td>.527</td>
</tr>
<tr>
<td>I’m afraid to talk about diabetes with my parents</td>
<td>.489</td>
<td>.285</td>
<td>-.026</td>
<td>.002</td>
<td>.393</td>
</tr>
<tr>
<td>My parents nag me to check my blood sugar</td>
<td>.759</td>
<td>.191</td>
<td>.106</td>
<td>.171</td>
<td>.590</td>
</tr>
<tr>
<td>My parents get mad if I forget to exercise</td>
<td>.648</td>
<td>.181</td>
<td>.098</td>
<td>.171</td>
<td>.427</td>
</tr>
<tr>
<td>My parents nag me about not taking care of my diabetes</td>
<td>.525</td>
<td>.095</td>
<td>-.158</td>
<td>.139</td>
<td>.473</td>
</tr>
<tr>
<td>If I have a problem taking care of my diabetes, my parents will help</td>
<td>.308</td>
<td>.812</td>
<td>.239</td>
<td>.182</td>
<td>.661</td>
</tr>
<tr>
<td>My parents explain diabetes care to my teachers</td>
<td>.383</td>
<td>.832</td>
<td>.282</td>
<td>.374</td>
<td>.699</td>
</tr>
<tr>
<td>I can talk to my parents about having diabetes</td>
<td>.221</td>
<td>.816</td>
<td>.211</td>
<td>.337</td>
<td>.677</td>
</tr>
<tr>
<td>My parents pay attention when I ask for help with taking care of my diabetes</td>
<td>.202</td>
<td>.753</td>
<td>.060</td>
<td>.204</td>
<td>.628</td>
</tr>
<tr>
<td>My parents tell me when I do a good job taking care of my diabetes</td>
<td>.164</td>
<td>.537</td>
<td>.196</td>
<td>.094</td>
<td>.338</td>
</tr>
<tr>
<td>My parents decide how much insulin I take</td>
<td>.143</td>
<td>.213</td>
<td>.810</td>
<td>.107</td>
<td>.548</td>
</tr>
<tr>
<td>My parents are responsible for reminding me to take my insulin</td>
<td>.176</td>
<td>.250</td>
<td>.722</td>
<td>.234</td>
<td>.689</td>
</tr>
<tr>
<td>My parents do the carb counting for me</td>
<td>.074</td>
<td>.220</td>
<td>.739</td>
<td>.151</td>
<td>.412</td>
</tr>
<tr>
<td>My parents watch me give my bolus or fast-acting insulin at meal times</td>
<td>.155</td>
<td>.205</td>
<td>.254</td>
<td>.716</td>
<td>.666</td>
</tr>
<tr>
<td>My parents watch me draw-up my insulin (or watch me set my pump)</td>
<td>.065</td>
<td>.229</td>
<td>.146</td>
<td>.808</td>
<td>.698</td>
</tr>
<tr>
<td>My parents look at my meter’s (and/or pump’s) log</td>
<td>.056</td>
<td>.265</td>
<td>.226</td>
<td>.617</td>
<td>.534</td>
</tr>
<tr>
<td>My parents look at my ketone strip</td>
<td>.151</td>
<td>.344</td>
<td>.330</td>
<td>.808</td>
<td>.552</td>
</tr>
</tbody>
</table>

*Note.* Numbers in bold-face type represent items with the highest loadings on each factor. D–FAM = Diabetes Family Adherence Measure.
Convergent Validity

Intercorrelations between D–FAM subscale scores (see Table 2) suggest separate yet related constructs. In addition, correlations between D–FAM scores and extant measures of diabetes-specific family functioning suggest convergent and divergent validity (see Table 3). For example, the D–FAM coercion subscale relates most strongly with the DFBC non-supportive subscale and inversely with the DFBS WC subscale. However, the D–FAM coercion subscale does not relate with the DFBC GC and the DFRQ no–responsibility subscales, providing initial support for discriminant validity.

Construct Validity

Table 3 also presents correlations between the D–FAM and parent-youth reports of adherence. HbA1c related to D–FAM support \(r = -0.37\), coercion \(r = 0.39\),

<table>
<thead>
<tr>
<th>D–FAM Items</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Support</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Coercion</td>
<td>-0.43**</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Monitoring</td>
<td>0.51**</td>
<td>-0.22**</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>4. Control</td>
<td>0.41**</td>
<td>-0.20*</td>
<td>0.36**</td>
<td>1</td>
</tr>
</tbody>
</table>

**Note.** D–FAM = Diabetes Family Adherence Measure.

**p < .01.** **p < .001.

TABLE 2
Interrelations Between D–FAM Scores

<table>
<thead>
<tr>
<th>D–FAM Items</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coercion</td>
<td>-0.43**</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Monitoring</td>
<td>0.51**</td>
<td>-0.22**</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Control</td>
<td>0.41**</td>
<td>-0.20*</td>
<td>0.36**</td>
<td>1</td>
</tr>
</tbody>
</table>

**Note.** D–FAM = Diabetes Family Adherence Measure.

* \(p < .01.** **p < .001.

TABLE 3
Interrelations Between D–FAM Scores and Validity Measures

<table>
<thead>
<tr>
<th>D–FAM Items</th>
<th>DFBC–CN</th>
<th>DFBS WC</th>
<th>DFBS GC</th>
<th>DFRQ NR</th>
<th>DSMP–Parent</th>
<th>DSMP–Child</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support</td>
<td>-0.35***</td>
<td>.30***</td>
<td>.10</td>
<td>-0.16</td>
<td>.29***</td>
<td>.33***</td>
</tr>
<tr>
<td>Coercion</td>
<td>-0.65***</td>
<td>.22***</td>
<td>.14</td>
<td>-0.14</td>
<td>.35***</td>
<td>.23***</td>
</tr>
<tr>
<td>Monitoring</td>
<td>-0.22**</td>
<td>-0.09</td>
<td>.20**</td>
<td>-0.26***</td>
<td>.21***</td>
<td>.17*</td>
</tr>
<tr>
<td>Control</td>
<td>-0.15</td>
<td>.12</td>
<td>.22**</td>
<td>-0.20**</td>
<td>.18*</td>
<td>.25***</td>
</tr>
</tbody>
</table>

**Note.** D–FAM = Diabetes Family Adherence Measure; DFBC–CN = Diabetes Family Behavior Checklist–Child-Rated Negativity; DFBS = Diabetes Family Behavior Scale; WC = warmth/caring subscale; GC = guidance/control subscale; DFRQ NR = Diabetes Family Responsibility Questionnaire no–responsibility index; DSMP = Diabetes Self-Management Profile.

* \(p < .05.** **p < .01.*** p < .001.
and control ($r = -.24$; all $ps < .001$), but not monitoring ($r = -.11$, $p = .10$). The frequency of DKA also related to D–FAM coercion ($r = .30$). Overall, increased coercive behavior related to worse adherence, metabolic control, and more episodes of DKA. More supportive behavior and control related to better adherence and metabolic control. Increased parental monitoring related to higher adherence.

Incremental Validity

The D–FAM demonstrated incremental validity (Haynes & Lench, 2003) over extant measures of family functioning (DFRQ, DFBC, DFBS WC, and DFBS GC) in the prediction of HbA1c ($R^2 = 18$, $F(4, 114) = 6.40$, $p < .001$).

Test-Retest Reliability

Two-week test–retest data were collected for 17.5% ($n = 28$) of respondents participating in this research. Approximately 30% of participants (every third participant recruited) were asked to complete test–retest data (2 refused, citing time constraints). Thus, approximately 60% of participants whom were asked to complete test–retest data and agreed returned the measures within a requested 2-week period. MANOVA, used to analyze differences between participants completing test–retest data and youth in the overall sample who did not complete the test–retest, was nonsignificant for group differences, suggesting that completers of the test–retest data did not differ, relative to the overall sample on HbA1c, DKA, demographic variables, parent-youth reports of adherence, and D–FAM scores. Strong, positive correlations between the original administration and the retest administration were identified for supportive ($r = .83$), coercive ($r = .85$), monitoring ($r = .79$), and control ($r = .77$; all $ps < .001$).

Development of the Social Desirability Scale

We retained four of the original set of eight questions designed as potential validity and social desirability indicators given their non-normal distribution patterns (less than 8% of the sample responding on the high-end anchor choice; only the 4 items with highly skewed response patterns were retained; DeVellis, 2003; Strahan & Gerbasi, 1972). The items are listed in the Appendix. Less than 4% of the sample endorsed “always” on two of these four items. Coefficient alpha was low for this scale (0.38), which is not surprising given the short length of the scale, variability of content, skewed distribution of responses, and low overall responses. In addition, test–retest reliability was low ($n = 28$; $r = .21$, $p = .50$), which is also not surprising given that endorsing “always” on these
items was markedly atypical. There was insufficient power to compare group differences between youth who endorse atypical items versus the remainder of the sample.

**DISCUSSION**

This research has addressed the development and validation of the D–FAM, a youth-report measure of adherence-related parent–child relationship processes for youth with T1D. The development and evaluation of the D–FAM followed an empirical approach for scale design (Worthington & Whittaker, 2006). Factor analysis of the D–FAM produced a four-factor solution representing parental support, coercion, monitoring, and control specific to diabetes. Subscales demonstrated strong internal consistency, test–retest reliability, convergent and divergent validity, and construct validity.

Internal consistency and test–retest reliability were used as indexes of reliability. Acceptable internal consistency was found for each of the D–FAM subscales, suggesting that items within each subscale contribute to the overall subscale’s score. Strong test–retest correlations were also found. High associations between initial reports and 2-week retests are promising given that family functioning is believed to be a relatively stable construct. Correlations were strong and significant, despite the low number of youth completing the retest administration. Further, our data suggested that children who were retested were representative of the overall sample. Overall, data from our sample support reliability of the D–FAM and the four-factor structure.

A strong, initial analysis of the D–FAM’s validity was also conducted. First, concurrent validity was assessed via comparisons with extant measures of diabetes-specific family functioning. Relations with extant measures were found in the expected directions. Moderate to strong correlations were found between the D–FAM factors and HbA1c, child-parent reports of regimen adherence, and (although somewhat weaker) with the frequency of prior DKA. In addition, discriminant validity was also demonstrated in that D–FAM subscales correlated with extant measures covering similar content (e.g., D–FAM control related to DFBC GC and DFRQ no-responsibility, but not with DFBC non-supportive parenting and DFBS WC).

Of note, despite the initial inclusion of a number of items addressing insulin pump behaviors, insulin-to-carbohydrate ratios, and mixing insulin, these items did not meet criteria for inclusion on the D–FAM. A possible explanation is that more general diabetes care tasks, rather than regimen-specific tasks, appeared more favorable in a broad sample. Future analyses could examine family functioning differences among youth with intensive insulin therapy versus other protocols. Overall, the items in our measure appear robust to a number
of diabetes regimens (e.g., D–FAM language applies to insulin pump users, intensive insulin regimens), although future research could provide empirical support. The addition of the Social Desirability Scale must be considered exploratory because we had insufficient power to evaluate group differences. However, this scale produced a subset of items rarely endorsed, and can suggest attention to be directed to any respondent endorsing these items, especially given that less than 4% of our sample endorsed “always” on two or more of these items.

Overall, findings of this study offer support and extensions to extant literature on diabetes family functioning. For example, consistent with previous studies, better adherence and health status was found in youth whose parents were rated as displaying increased positive emotional support (e.g., expressing understanding regarding the difficulties of living with diabetes, being approachable to discuss diabetes-related topics, and relating to their child about having diabetes; La Greca et al., 1995; Lewin, Geffken, et al., 2005; Lewin et al., 2006; Schafer et al., 1986; Waller et al., 1986). Conversely, harsh and critical parental behavior patterns surrounding diabetes care activities (e.g., nagging, scolding, and yelling) related to worse adherence and metabolic control (Anderson et al., 1997; Hood et al., 2007; Lewin et al., 2006; Miller-Johnson et al., 1994; Schafer et al., 1986). In addition, appropriate parental monitoring and control and supervision of diabetes care tasks was related to adherence (Anderson et al., 1990; Anderson et al., 1997; Anderson & Laffel, 1997; Weissberg-Benchell et al., 1995; Wiebe et al., 2005; Wysocki et al., 1996).

This study also documented a strong interrelation between diabetes adherence-related family factors (e.g., support, coercion, monitoring, and control) while also suggesting that these factors represent separate constructs. This is consistent with theories suggesting that multiple related, albeit independent, family processes are embedded in diabetes self-care in youth (Anderson & Laffel, 1997; Lewin et al., 2006; McKelvey et al., 1993). Although beyond the aims of the research presented in this study, future analyses could employ the D–FAM to elucidate the developmental pattern of adherence-related family factors. Specifically, prior research suggests that certain family processes (e.g., control, guidance, and monitoring) are of higher importance in preadolescents (Anderson et al., 1997; Waller et al., 1986), whereas others are relevant through multiple age spans. A recent developmental study suggested that adolescent independence in self-care may be favorable long-term outcomes (autonomy), but negative short-term consequences and risk of poor health outcomes (Butner et al., 2009). Through longitudinal research (or larger cross-sectional studies), the D–FAM may assist researchers in understanding how specific diabetes-related family processes affect adherence and health status as a child matures.

There are a number of limitations regarding this research. First, a larger sample size may have allowed the inclusion of additional items and possibly
the identification of additional factors and allowed for a statistical evaluation of the Social Desirability Scale. Second, this study lacks a parent D–FAM—development of a parent report version would allow for parent-youth comparisons and provide additional perspectives of family functioning. Third, characteristics of this sample (e.g., low income and relatively high occurrence of DKA) may also limit generalization of findings. Fourth, although our sample may be appropriate for validation, a larger, representative sample is needed for normative purposes and replication of the factor structure using confirmatory techniques. Fifth, longitudinal analysis of the D–FAM could provide long-term stability estimates for the D–FAM, as well as tracing developmental changes in diabetes-related family functioning. Finally, estimates of DKA are based on retrospective parental report and, consequently, may be inaccurate.

Implications for Practice

The D–FAM provides a clinical research tool for the assessment of family behaviors that corresponds with adherence to the diabetes treatment regimen and has been linked to diabetes-related health status. Despite the utility of extant measures of family functioning, the technology of diabetes treatment regimen has increased exponentially over the past decade. It stands to reason that the resources of the family to cope with the increased complexity have become increasingly taxed. Given the complex, challenging, and often stress-inducing nature of diabetes treatment regimen, there is a clear role of behavioral health experts in helping family members understand and adjust to the requirements of the child’s diabetes regimen (La Greca & Mackey, 2009; Lewin, Storch, Silverstein, et al., 2005). More specifically, researchers and clinicians posited that improving adherence and glycemic control in youth with T1D must involve changes within the family system; recent controlled investigations are targeting these factors (Wysocki et al., 2000). Consequently, practical and valid measurement (robust to various diabetes regimens) of these family processes is indicated. Information gathered from a comprehensive assessment of family functioning (as assessed by the D–FAM) would be useful in both research evaluation and clinical treatment planning including examination of current perceptions of the child, as well as changes over time.

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REFERENCES


## APPENDIX
### Diabetes Family Adherence Measure (D–FAM)

**Directions:** Please circle the answer that best describes what happened or didn’t happen in your family during the past 3 months. Circle only 1 answer. There are no right or wrong answers; just circle what happens in your family. If you are not sure, make your best guess.

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>Never True</th>
<th>A little of the time true</th>
<th>Sometimes true</th>
<th>A lot of the time true</th>
<th>Always True</th>
</tr>
</thead>
<tbody>
<tr>
<td>S 1</td>
<td>My parents tell me when I do a good job taking care of my diabetes</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>C 2</td>
<td>My parents decide how much insulin I take</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>R 3</td>
<td>My parents blame me when my blood sugar is too high</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>S 4</td>
<td>My parents pay attention when I ask for help with taking care of my diabetes</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>M 5</td>
<td>My parents watch me draw-up my insulin (or watch me set my pump)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>M 6</td>
<td>My parents look at my ketone strip</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>V 7</td>
<td>I check ketones 6 times every day</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>R 8</td>
<td>I get yelled at if I forget my insulin</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>R 9</td>
<td>My parents and I argue because of my diabetes</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>C 10</td>
<td>My parents do the carb counting for me</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>V 11</td>
<td>I eat exactly what I should every time</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>M 12</td>
<td>My parents watch me give my bolus or fast-acting insulin at meal times</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>R 13</td>
<td>I’m afraid to talk about diabetes with my parents</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>S 14</td>
<td>My parents explain diabetes care to my teachers</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>S 15</td>
<td>I can talk to my parents about having diabetes</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>R 16</td>
<td>My parents nag me to check my blood sugar</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>V 17</td>
<td>My blood sugar is always between 80 and 120</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>C 18</td>
<td>My parents are responsible for reminding me to take my insulin</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>R 19</td>
<td>My parents get mad if I forget to exercise</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>M 20</td>
<td>My parents look at my meter’s (and/or pump’s) log</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>V 21</td>
<td>I’m glad I have diabetes</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>R 22</td>
<td>My parents nag me about not taking care of my diabetes</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>S 23</td>
<td>If I have a problem taking care of my diabetes, my parents will help</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

*Note.*  S = support;  R = coercion;  M = monitoring;  C = control;  V = validity.