Assessing Health-Related Quality of Life in Children and Adolescents with Diabetes: Development and Psychometrics of the Type 1 Diabetes and Life (T1DAL) Measures

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Abstract

Objective To develop and validate new measures of diabetes-specific health-related quality of life (HRQOL) for people with type 1 diabetes (T1D) that are brief, developmentally appropriate, and usable in clinical research and care. Here we report on the phases of developing and validating the self-report Type 1 Diabetes and Life (T1DAL) measures for children (age 8–11) and adolescents (age 12–17). **Methods** Measure development included qualitative interviews with youth and parents ($n = 16$ dyads) followed by piloting draft measures and conducting cognitive debriefing with youth ($n = 9$) to refine the measures. To evaluate the psychometric properties, children ($n = 194$) and adolescents ($n = 257$) at three T1D Exchange Clinic Network sites completed the age-appropriate T1DAL measure and previously validated questionnaires measuring related constructs. Using psychometric data, the investigators reduced the length of each T1DAL measure to 21 and 23 items, respectively, and conducted a final round of cognitive debriefing with six children and adolescents. **Results** The T1DAL measures for children and adolescents demonstrated good internal consistency ($\alpha = 0.84$ and 0.89 , respectively) and test–retest reliability ($r = 0.78$ and 0.80 , respectively). Significant correlations between the T1DAL scores and measures of general quality of life, generic and diabetes-specific HRQOL, diabetes burden, and diabetes strengths demonstrated construct validity. Correlations with measures of self-management (child and adolescent) and glycemic control (adolescent only) demonstrated criterion validity. Factor analyses indicated four developmentally specific subscales per measure. Participants reported satisfaction with the measures. **Conclusions** The new T1DAL measures for children and adolescents with T1D are reliable, valid, and suitable for use in care settings and clinical research.

Key words: developmental perspectives; diabetes; quality of life.

Quality of life (QOL) is an important patient-reported outcome that represents an individual's subjective perception of their overall well-being, satisfaction with daily life, ability to participate in work and leisure activities, emotional status, and social engagement. For youth, QOL reflects developmentally appropriate functioning in social, emotional, and physical domains (Wallander, Schmitt, & Koot, 2001). One component of QOL, health-related QOL (HRQOL), measures an individual's well-being with respect to their physical health, including general health status (e.g., physical strength, fatigue), worries about health, the impact of a specific health condition on physical, social, and emotional functioning, and satisfaction with the status and treatment of a health condition (Levi & Drotar, 1998). Instruments that measure HRQOL can capture the impact of having a health condition in general (generic HRQOL) or a particular condition (e.g., diabetes-specific HRQOL). Clinical trials are increasingly incorporating patient-reported outcomes including HRQOL as a primary study outcome (Lohr & Zebrack, 2009).

For people with type 1 diabetes (T1D), better diabetes-specific HRQOL predicts more engagement in self-management behaviors and lower hemoglobin A1c (HbA1c) (Hilliard et al., 2013; Hoey et al., 2001; Hood et al., 2014), emphasizing its central role in diabetes-related health. In this context, reliable and valid measurement of diabetes-specific HRQOL is essential for clinical research to draw accurate and meaningful conclusions that can influence treatment. National and international practice guidelines are also increasingly recommending that healthcare providers use HRQOL instruments to screen and improve patient care (Delamater et al., 2018; Drotar et al., 1998a; Young-Hyman et al., 2016). In addition, intervention research suggests that routinely monitoring and discussing HRQOL with adolescents with T1D and their families improves well-being and may ultimately affect health outcomes (de Wit et al., 2008).

Expert reviews have identified substantial gaps in the existing validated measures of diabetes-specific HRQOL (de Wit, Delemarre-van de Waal, Pouwer, Gemke, & Snoek, 2007; Fisher, Tang, & Polonsky, 2016; Speight, Reaney, & Barnard, 2009; Tang, Yusuf, Polonsky, & Fisher, 2017), highlighting the need for new instruments that address these limitations. Table I summarizes the characteristics of commonly used HRQOL measures for youth and highlights concerns related to the quality of the measures, including psychometrics (e.g., reported reliability and validity data), the degree to which items focus on negative aspects of HRQOL to the exclusion of

assessing any positive aspects of HRQOL, and issues with the degree of developmental tailoring/appropriateness for youth at different ages.

As noted in the table, psychometric concerns are common, including some measures that fail to report reliability or validity in the target population. Factor analysis is rarely conducted to identify subscales, and Nansel et al. (2008) and Varni et al. (2018) have reported issues with low subscale reliability (e.g., factor structure, internal consistency) for versions of the Pediatric Quality of Life Inventory (PedsQL) Diabetes Module, one of the most commonly used measures. Validity is also an important concern. Some measures exhibit poor face validity, such as item quantity and content that emphasizes physical symptoms/problems rather than daily experience living with diabetes. As noted in the table, most diabetes-specific HRQOL measures for youth focus on problems encountered by individuals with diabetes, such as physical symptoms related to diabetes, problems with diabetes management (e.g., worries, barriers to engaging in self-management behaviors, and difficulty communicating about diabetes), and feeling bothered by life experiences because of diabetes (McMillan, Honeyford, Datta, Madge, & Bradley, 2004; Varni et al., 2018). This focus may lead to not assessing the full range of concepts that make up HRQOL and missing important positive aspects of living with diabetes (e.g., areas of success, self-efficacy, and feeling supported). As a result, commonly used HRQOL measures often assess constructs that are related to but distinct from diabetes-specific HRQOL, and may be confounded with other key outcomes, such as physical (e.g., disease symptoms, physical abilities, or limitations) or emotional problems (e.g., depressive symptoms, stress, and diabetes-related burden) (Fisher et al., 2016). Other face validity concerns include outdated items that are not relevant to current diabetes treatments and use of regional terminology/country-specific references (e.g., items about respondent involvement in British Diabetes Association activities; McMillan et al., 2004).

Finally, many diabetes-specific HRQOL measures are designed for particular ages of youth with T1D (Baars et al., 2005; de Wit et al., 2012; Ingersoll & Marrero, 1991; McMillan et al., 2004), making it difficult to measure HRQOL longitudinally or at different points in the lifespan. Instruments validated only with a specific age range are not appropriate for use with older or younger youth. Some measures have validation age ranges that cross developmental stages, raising questions about the appropriateness of the content for all respondents. Among measures with versions validated for multiple ages, item content is rarely

Table 1. Existing Diabetes-Specific HRQOL Measures

Instrument name	References	Ages	Reporter	No. Items	Domains	Statistically derived factors	Psychometric (reliability, validity) Concerns	Developmental tailoring concerns	Problem-focused items
Audit of Diabetes Dependent Quality of Life-Teen (ADDQoL-Teen)	McMillan et al. (2004)	13–18 years	Self	25	General QOL, Overall T1D QOL, Frequency and Bothered by each item because of T1D	Impact-self, Impact-others	No data reported on content or criterion validity compared to other measures	No psychometric data published for versions for younger children	Yes
Diabetes-Specific Quality of Life – Youth (DQOLY)	Ingersoll and Marrero (1991)	11–18 years	Self	52	Diabetes Life Satisfaction, Impact, Worries	None	Reliability not reported	Only available for adolescents	Yes
DISABKIDS-DM	Baars et al. (2005); Chaplin, Hallman, Nilsson, and Lindblad (2012)	8–16 years	Self	10	Not specified	Impact, treatment	Validity not reported, limited diabetes-specific data reported (Swedish only)	Age range 8–18 years, crosses developmental stages (child, adolescent) without differentiation	Yes
KINDL-R-DM	Ravens-Sieberer and Bullinger (2001)	7–13 years	Self	17	Not specified	None reported	Not published for diabetes specific version	Only available for ages 7–13	Yes
MIND-Youth Questionnaire	de Wit et al. (2012)	10–18 years	Self	36	General QOL, My Life (School/Work, Friends, Free Time, Family), My Self (Mood, Body/Weight), My Diabetes, Open-ended questions	Social impact, Parents, Diabetes control perceptions, Responsibility, Worries, Treatment satisfaction, Body image and eating behavior, Mood	Limited validity data reported in relation to PedsQL and HbA1c	Only available for adolescents	No
PedsQL Diabetes Module V3.2	Varni et al. (2018)	2–4 years, 5–7 years, 8–12 years, 13–18 years, 19–25 years	Self, Parent-Proxy	33	Problems with: Diabetes Symptoms, Treatment Barriers, Treatment Adherence, Worry, Communication	Diabetes symptoms summary score, Diabetes management summary score	Subscales did not replicate in factor analysis, questions raised about face validity of items/subscales	Items/subscales not created for developmental concerns of each age ranges, minor wording differences only	Yes

generated specifically for the issues relevant to different developmental stages (e.g., childhood vs. adolescence) and adaptations of the measures' content, wording, or format for different developmental stages tend to be minimal. Absent or superficial attention to measures' appropriateness for respondents at different levels can reduce their accuracy, validity, and clinical utility (Levi & Drotar, 1998).

Given the limitations of existing diabetes-specific HRQOL measures, there is a need to design and validate new measures that are brief, clinically relevant, psychometrically sound, and developmentally appropriate. Providing options for assessment of diabetes-specific HRQOL will allow researchers and clinicians to select tools that best meet their needs and most accurately reflect their conceptualizations of this important construct. Therefore, the aims of this study were to design and evaluate the psychometric properties of a suite of developmentally tailored measures of diabetes-specific HRQOL for youth with T1D, called "Type 1 Diabetes and Life" (T1DAL). This was part of a larger project to create and validate measures of HRQOL for people with T1D from childhood through older adulthood and for their parents and partners. Here, we present two T1DAL measures for youth with T1D: children (age 8–11 years) and adolescents (age 12–17 years). The age-bands were selected consistent with accepted categorizations of developmental stages (Centers for Disease Control and Prevention, 2019; Peters & Laffel, 2013). We hypothesized that the T1DAL-Child and T1DAL-Adolescent measures, designed with input from youth with T1D and their family members and healthcare providers, would demonstrate psychometric validity (i.e., construct and criterion validity) and reliability (i.e., internal consistency, test–retest reliability). Exploratory factor analyses aimed to identify subscales for each measure.

Methods

The research team developed and validated the new measures in multiple steps, per measure development guidelines (Drotar et al., 1998b; Holmbeck & Devine, 2009). The goal of Phase 1 was to develop, pilot, and refine measures based on existing measures and literature, as well as input from youth with T1D and their parents and diabetes care providers. The goal of Phase 2 was to evaluate the psychometric properties and factor structure of the new measures in a large national sample, and to shorten the measures based on the results. The goal of Phase 3 was to receive feedback about the measures that resulted from Phase 2, to inform any final modifications to the measures. The relevant institutional review boards approved each phase. In each

phase, study staff described the study to potential participants, answered questions, and evaluated understanding prior to enrollment. Youth provided assent and parents provided written consent. Participants received modest incentives in appreciation of their completion of study procedures.

Recruitment and Enrollment

Phase 1 recruitment took place at Texas Children's Hospital (Houston, TX). After reviewing existing instruments and literature, the study team generated a preliminary list of HRQOL topics for potential inclusion as items in the new measures. Study staff conducted qualitative interviews with youth with T1D and their parents to identify aspects of diabetes-specific HRQOL to include. Study staff reviewed patient schedules from the diabetes care clinic at the hospital's main campus to identify potentially eligible youth with upcoming medical appointments. Inclusion criteria were youth age 8–17, T1D diagnosis for at least 12 months, and fluency in written/spoken English. Exclusion criteria included the parent or child having a significant comorbid medical, cognitive, or mental health condition that would interfere with their ability to participate in the interviews. Study staff sent potentially eligible participants informational letters about the study with an option to opt out of being approached about the study and followed up by telephone to introduce the study and schedule a study visit, either on the same day as a medical visit or at a separate time. At the study visit, research staff obtained written informed consent and assent. We mailed letters to 40 families of children ages 8–17. Of the 21 eligible people contacted before enrollment was complete, 16 (76%) consented and completed the interview. Participant demographic and clinical characteristics are summarized in Table II. The investigators then created draft versions of the T1DAL measures for each age range. To pilot and obtain feedback about the draft measures, staff recruited nine new participants ($n=5$ age 8–11, $n=4$ age 12–17) at Texas Children's Hospital using the same procedures (Table II).

Phase 2 took place at three pediatric diabetes care centers within the T1D Exchange Clinic Network: Children's Hospital of Los Angeles (Los Angeles, CA), Barbara Davis Center for Diabetes (Denver, CO), and Vanderbilt University School of Medicine (Nashville, TN). The investigators selected the sites based on geographic and demographic diversity, as well as history of successful recruitment through the T1D Exchange Clinic Registry and associated studies. To recruit participants, study staff at each site reviewed diabetes clinic schedules to identify potentially eligible families. Inclusion and exclusion criteria were the same as in Phase 1. When possible, study staff recruited

Table II. Participant Characteristics by Study Phase

Clinical and demographic characteristics	Phase 1: Qualitative	Phase 1: Debriefing	Phase 2: Children	Phase 2: Adolescents	Phase 3
N	16	9	194	257	6
Age, <i>M</i> (<i>SD</i>), years	12.9 (2.5)	12.3 (2.4)	10.2 (1.1)	15.0 (1.8)	13.0 (3.0)
Gender, % (<i>n</i>) female	44 (7)	22 (2)	48 (93)	46 (118)	50 (3)
Race/Ethnicity, % (<i>n</i>) non-Hispanic White	31 (5)	22 (2)	63 (122)	58 (150)	83 (5)
HbA1c, <i>M</i> (<i>SD</i>)	8.9 (1.8)	8.0 (1.3)	8.2 (1.2)	8.7 (1.7)	7.5 (0.7)
T1D duration, <i>M</i> (<i>SD</i>), years	4.6 (3.2)	5.5 (4.4)	4.7 (2.5)	7.0 (3.6)	7.7 (2.2)
Insulin regimen, % (<i>n</i>) pump	38 (6)	56 (5)	62 (121)	61 (157)	100 (6)
Validation measures, <i>M</i> (<i>SD</i>)					
Life overall			8.3 (1.8)	7.7 (1.7)	
PedsQL diabetes			69.3 (12.3)	67.4 (14.6)	
PedsQL generic			81.2 (13.4)	80.5 (14.9)	
SWLS			26.3 (6.3)	24.2 (7.2)	
PAID			54.1 (24.2)	60.0 (28.0)	
DSTAR			35.5 (9.5)	35.2 (8.7)	
SCI			72.0 (16.8)	68.2 (16.2)	

Note. HbA1c = hemoglobin A1c; PedsQL = Pediatric Quality of Life Inventory; SWLS = Satisfaction with Life Scale; PAID = Problem Areas in Diabetes scale; DSTAR = Diabetes Strengths and Resilience measure; SCI = Self-Care Inventory.

participants already enrolled in the T1D Exchange Clinic Registry to permit access to already-collected demographic data. Most sites sent informational letters about the study to potentially eligible participants, and study staff at all sites met with families at diabetes clinic visits to describe the study, confirm eligibility, answer questions, and obtain informed consent (parents) and assent (youth). Participants consented to completing questionnaires on two occasions and to granting access to their medical record and data already collected through the Clinic Registry. Across the three sites, 496 families of youth ages 8–17 years consented and enrolled in the study. In the 8–11 (child) age-band, 215 participants enrolled and final T1DAL scores were calculable for $n = 194$ (90%; $n = 21$ did not complete any items). In the 12–17 (adolescent) age-band, 281 participants enrolled and final T1DAL scores were calculable for $n = 257$ (91%). See [Table II](#) for participant characteristics.

For Phase 3, following psychometric analyses, the investigators advertised on Twitter to recruit a new sample of 2–3 participants per age-band to complete a final review of the resulting measures. Interested English-fluent people in the United States and other countries contacted the study team through direct message, email, or telephone. Study staff called and explained the study, determined eligibility, answered questions, and obtained written informed consent (via postal mail or scanned and emailed). All of the six children and adolescents whose parents contacted the study team were eligible and participated ([Table II](#)).

Procedures

For Phase 1, study staff conducted individual qualitative interviews using semi-structured interview scripts

(Example questions in [Supplementary Online Appendix 1](#)). For most participants, the parent was not in the room for the interview. An expert in qualitative research trained staff to establish rapport to facilitate open conversation, ask open-ended questions per the scripts, and use prompts and probes to elicit additional comments or clarify responses. The scripts aimed to elicit comments about multiple areas of HRQOL including family interactions around T1D; experiences with T1D at school, with friends, and during activities; and thoughts and feelings related to living with T1D. Interviewers also invited participants to discuss any other topics related to T1D that they felt were important. The interviewers audio-recorded the interviews and professional medical transcriptionists transcribed the recordings and removed personal identifiers. Parents also provided information about family demographics and consented for staff to conduct medical chart reviews to ascertain data about the youth's diabetes history and clinical characteristics (e.g., date of diagnosis, most recent HbA1c).

Based on this process, the investigators created drafts of the T1DAL measures, following the format of the Mind Youth-Questionnaire (MY-Q, [de Wit et al., 2012](#)), a measure of diabetes-specific HRQOL validated for use in adolescents with T1D. The study team (led by three behavioral scientists with expertise in diabetes) designed the items to reflect the themes from the qualitative interviews and previous literature and to include both challenges and positive aspects of diabetes-specific HRQOL. We used developmentally appropriate vocabulary, simple sentence structure, and aimed for an elementary school reading level to facilitate understanding by youth ([Levi & Drotar, 1998](#)). Expert collaborators reviewed the draft measures and provided feedback.

To pilot the draft T1DAL measures, study staff instructed a new sample of participants to complete the measure and mark any questions or items that were unclear or hard to answer, then completed structured cognitive interviews (Example questions in [Supplementary Online Appendix 2](#)). The interviewers asked participants to comment on any items/words that were confusing, uncomfortable to answer, repetitive, or unimportant, and to explain how easy or hard it was to answer each item, what they thought about while answering, questions about how they interpreted specific items/phrases, and suggestions to improve problematic items. Finally, staff asked participants how they would feel about their diabetes care providers giving them this questionnaire in clinic, and if there were any other topics related to living with T1D that they felt should have been included. Interviews were audio-recorded and professionally transcribed. Interviewers summarized the responses to these interviews and based on this feedback, the study team edited item wording and omitted confusing or difficult items.

For Phase 2, participants and parents completed questionnaires (see Measures) via a web-based, secure survey portal to complete questionnaires on two occasions: at the time of enrollment and again 4–6 weeks later (secure link sent via email to participants and parents). Participants could complete the questionnaires in clinic before or after their regularly scheduled medical visits, or from home. Study staff also completed chart reviews to document demographic and clinical data.

For Phase 3, study staff emailed the age-appropriate measure to participants and asked them to time themselves while completing the measure. Then, by telephone, the interviewer followed a similar script as the Phase 1 cognitive interviews to evaluate participants' perceptions about the measures' clarity, appropriateness, and redundancy. Interviews were audio-recorded and professionally transcribed. Interviewers summarized the responses from participants and expert collaborators also provided feedback. The investigators made final decisions about items to keep or drop based on participant and expert feedback.

Measures

In Phase 2, participants completed the age-appropriate T1DAL measure and previously validated measures of constructs related to diabetes-specific HRQOL to assess construct validity at baseline. At follow-up, participants completed the T1DAL measure again to assess test–retest reliability. The T1DAL measures used in the validation study were comprised of 34 and 42 items for the versions for children (ages 8–11) and adolescents (age 12–17), respectively. Instructions

directed participants to rate each item on a scale of 0–4 (No, not at all true to Yes, very true) indicating the degree to which each item represented their experience over the previous 4 weeks. Items were presented in conceptual categories, such as “Diabetes at School” and “Diabetes and How I Feel” and included boxes for participants to indicate whether individual items or groups of items were not applicable to them. The Fleisch-Kincaid Grade Level for the Child version was 6.7, and for the Adolescent version was 6.5. Item scoring used a scale of 0–100; positively worded items were scored 0 = 0, 1 = 25, 2 = 50, 3 = 75, or 4 = 100, and negatively worded items were scored in reverse, so that higher scores indicate better HRQOL. We calculated each subscale score and the total score by computing the mean and multiplying by 25 to create an easily interpretable score (higher scores indicate better HRQOL). To minimize the risk for individual items to be over-interpreted, we did not calculate subscale scores if there were more than 10% missing items: >1 missing item on a factor (>2 missing items for adolescent Factor 1), and we did not calculate a total score if there were >3 missing items overall.

Construct Validity Measures

General Quality of Life

Participants answered a single item from the MY-Q ([de Wit et al., 2012](#)), in which they rated their quality of life overall (not health-related) on a scale of 1 (worst) to 10 (best). Participants also completed the Satisfaction with Life Scale (SWLS; [Diener, Emmons, Larsen, & Griffin, 1985](#)), on which they reported their degree of agreement with five statements about their perspectives on their life, on a scale from 1 (strongly disagree) to 7 (strongly agree). The α s in this sample were 0.82 and 0.90, respectively.

HRQOL

Participants completed the age-specific versions of the PedsQL Generic Core Scales Version 4.0 (generic HRQOL; [Varni, Seid, & Kurtin, 2001](#)) and Diabetes Module Version 3.2 (diabetes-specific HRQOL; [Varni et al., 2018](#)), one of the most widely used HRQOL measures in pediatric diabetes. Respondents rated how much of a problem they have had with 23 generic HRQOL issues (Generic Core Scales) and 33 diabetes-specific HRQOL issues (Diabetes Module) related to their physical and emotional well-being. In this sample, the α s were 0.91 (Generic) and 0.89 (Diabetes) for children, and 0.93 (Generic) and 0.93 (Diabetes) for adolescents.

Diabetes-Related Burdens

Participants completed the Child or Teen version of the Problem Areas in Diabetes scale (PAID-C; [Evans et al., 2019](#); PAID-T: [Weissberg-Benchell & Antisdel-](#)

Lomaglio, 2011). Each PAID measure prompts respondents to rate how much of a burden each of 26 items is for them, on a 6-point scale (Not a problem to Serious problem). In this sample, the α s were 0.95 and 0.97, respectively.

Diabetes Strengths

Participants completed the Diabetes Strengths and Resilience measure (DSTAR-Child: Hilliard, Kushner, Hood, Weissberg-Benchell, & Anderson, 2015; DSTAR-Teen: Hilliard, Iturralde, et al., 2017) to assess adaptive feelings or behaviors related to diabetes. Respondents rate each of 12 items on a 5-point scale from never to almost always. The α s in this sample were 0.89 and 0.89, respectively.

Criterion Validity Measures

Self-Management Behaviors

Adolescents completed the Self-Care Inventory (SCI) (Lewin et al., 2009), a measure of frequency of completion of diabetes management behaviors on a 5-point scale (Never do it to Always do this as recommended without fail). Because the SCI is not validated for child self-report, parents completed the measure about their children age 8–11. The α s in this sample were 0.89 for parents of children and 0.87 for adolescent self-report.

Glycemic Control

Hemoglobin A1c (HbA1c) is an indicator of overall T1D-related health status and represents the average blood glucose over the past 2–3 months. Study staff extracted the point of care HbA1c value closest to study participation from each participant's medical chart.

Data Analyses

For Phase 1, the investigators followed guidelines for qualitative research methods (Wu, Thompson, Aroian, McQuaid, & Deatruck, 2016) and conducted hybrid thematic analysis using the qualitative interview transcripts (Braun & Clarke, 2006) using NVIVO software (Version 11). A research team comprised of three behavioral scientists with expertise in diabetes and three research coordinators developed a thematic codebook based on review of transcripts. The investigators identified common themes and decided on operational definitions. The research coordinators applied the codes to the transcripts and identified additional possible codes, which the research team discussed and added to the codebook. This process continued in multiple iterations until no new codes emerged. The coders double-coded 25% of transcripts and resolved any discrepancies through discussion. For the cognitive interviews that followed Phases 1 and 2, research staff summarized feedback

from participants and expert collaborators, and the PIs reviewed to make decisions.

For Phase 2, we conducted separate analyses for each age band. Responses to all T1DAL items underwent exploratory factor analysis using squared multiple correlations as prior communality estimates. We extracted factors using the maximum likelihood method, followed by a promax (oblique) rotation. We selected the number of meaningful factors for each age band based on assessment of scree plots, proportion of variance explained, and clinical interpretability. Using the data collected in the validation phase (Phase 2), we inspected the item properties to reduce measure length to approximately 20–25 items. The following decision rules guided the selection or deletion of items: no change in scale α if item dropped, $\geq 85\%$ response rate, no ceiling or floor effect, and significant loading (≥ 0.30) on at least one factor. When items loaded on two factors, we considered the size of the loading on each factor and the conceptual fit with each factor. Additional reasons to delete items were: items that assessed other constructs (e.g., engagement in/barriers to self-management) more than HRQOL, redundancy with another item (kept item with higher factor loading and/or better conceptual fit), or negative participant reactions to the item during cognitive debriefing. Each factor required at least three variables.

We estimated internal consistency (reliability) for multi-item questionnaires with Cronbach's α , and estimated validity and test-retest reliability with Pearson's correlations.

Results

In Phase 1, qualitative interviews generated themes related to many areas of diabetes-specific HRQOL, including family and social relationships, feelings about diabetes, and perceptions of the challenges and successes of managing T1D. Reporting the qualitative results is beyond the scope of the current paper; a selection of themes have been reported elsewhere (Cao et al., 2018; Eshtehardi et al., 2017a, 2017b, 2017c, 2018; Gonynor et al., 2017; Hilliard, Eshtehardi, et al., 2017; Pihlaskari et al., 2017; Wasserman et al., 2017). Cognitive debriefing generated suggestions from participants, which informed changes to each measure to enhance clarity (e.g., omitting confusing items, adding instructions about who is considered part of one's family), simplify language (e.g., change "I feel overwhelmed with everything I have to do for diabetes" to "Everything I have to do for diabetes feels like too much to handle"), reduce redundancy (i.e., removing items with similar content), and add "not applicable" response options (e.g., for items relating to dating in adolescent measure).

For the child version (age 8–11), we used responses from 194 participants in the factor analysis. The total score α was 0.88 (α with deleted variable, range = 0.87–0.88). Four factors emerged: Emotional Experiences (9 items), Self-Management Experiences (3 items), Support from Family & Others (6 items), and Family Conflict (3 items). See [Supplementary Online Appendix 3](#) for example items. These factors accounted for approximately 59%, 21%, 13%, and 8% of the common variance, respectively. After variable reduction, we retained 21 items for the final T1DAL-Child questionnaire. The total score α for the reduced item set was 0.84 (α with deleted variable, range = 0.82–0.84), Fleisch-Kincaid = 7.1.

For the adolescent version (age 12–17), we used responses from 257 participants for the factor analysis. The total score α was 0.92 (α with deleted variable, range = 0.91–0.92). Four factors emerged: Emotional Experiences & Daily Activities (11 items), Peer Relationships (3 items), Family Relationships (3 items), and Handling Diabetes Well (6 items). See [Supplementary Online Appendix 3](#) for example items. These factors accounted for approximately 70%, 12%, 10%, and 8% of the common variance, respectively. After variable reduction, we retained 23 items for the final T1DAL-Adolescent questionnaire. The total score α for the reduced item set was 0.89 (α with deleted variable range = 0.88–0.89), Fleisch-Kincaid = 6.7.

[Table II](#) presents the descriptive statistics for each validity measure. [Tables III](#) and [IV](#) summarize the reliability and construct and criterion validity data for the total scores and factor scores for each measure.

In Phase 3, participant feedback was largely positive: participants noted that the measures were easy to understand and captured many of their experiences living with T1D, and they felt comfortable answering the questions. Participants provided individual feedback about clarifying specific items. They reported the T1DAL measures took less than 10 min to complete.

Discussion

The new self-report T1DAL measures of diabetes-specific HRQOL for children age 8–11 and adolescents age 12–17 with T1D have strong psychometric properties and are suitable for use in clinical research and practice. The rigorous development and validation processes centered around input from youth with T1D and their family members, ensuring that the resulting measures reflect the experiences and perspectives of the target population. The brevity and clinical relevance of the content support the potential for use in busy healthcare and research settings.

The total scores of each measure indicated that children and adolescents reported moderate diabetes-specific HRQOL. We observed no ceiling or floor

Table III. T1DAL Total and Subscale Scores and Reliability Estimates

Age	Scale name	M $\pm$ SD	Internal consistency (α)	Test-retest (r)
8–11	Total	73.5 $\pm$ 13.8	0.84	0.78
	Emotional Experiences	65.3 $\pm$ 18.5	0.75	0.73
	Support from Family & Others	77.6 $\pm$ 13.7	0.39	0.65
	Self-Management Experiences	73.1 $\pm$ 20.02	0.50	0.50
	Family Conflict	90.6 $\pm$ 15.1	0.54	0.58
12–17	Total	62.1 $\pm$ 17.0	0.89	.80
	Daily Emotional Experiences & Daily Activities	48.5 $\pm$ 22.4	0.86	0.79
	Handling Diabetes Well	78.0 $\pm$ 16.3	0.74	0.62
	Peer Relationships	69.6 $\pm$ 22.2	0.53	0.56
	Family Relationships	72.5 $\pm$ 25.2	0.65	0.69

effects, and there is room for improvement in response to intervention ([de Wit et al., 2008](#); [Drotar et al., 1998a](#)). Both T1DAL measures demonstrated significant reliability and validity for the total scores. Each factor also demonstrated strong construct validity. Some factors had relatively low internal consistency, attributable to the intentionally small number of items per factor and efforts to minimize redundancy between items. The highly consistent significant associations between the T1DAL total scores and multiple validity measures (including other measures of QOL, diabetes distress, and diabetes strengths) indicate that these new instruments accurately assess the range of constructs that comprise HRQOL.

The T1DAL-Adolescent measure demonstrated criterion validity via significant correlations with self-management behaviors and glycemic control, indicating that the aspects of HRQOL that the measure assesses relate to important clinical outcomes. The T1DAL-Child total score also demonstrated criterion validity in relation to children's parent-reported self-management, but we did not observe a significant correlation with glycemic control. This null association with HbA1c is common and reflects that HbA1c and HRQOL are distinct constructs, each worth examining. In this age range, the lack of a significant correlation may be due to the typically higher level of parental involvement in diabetes care in children. Given the longstanding link of parental involvement with HRQOL and HbA1c ([Jaser, 2011](#)), it may overshadow the potential influence of children's HRQOL in relation to glycemic outcomes. Given these results, we recommend using the total T1DAL scores for all purposes and using caution with the subscale scores (i.e., examine α in study samples).

Table IV. *Validity Estimates for T1DAL Total and Subscale Scores*

Age	Scale	Life overall	PedsQL diabetes	PedsQL generic	SWLS	PAID	DSTAR	SCI°	HbA1c
8 -11	Total	.48**	.67**	.58**	.56**	−0.72**	.53**	.20**	−.07NS
	Emotional Experiences	.45**	.66**	.59**	.47**	−.71**	.39**	.16*	−.06NS
	Support from Family & Others	.35**	.46**	.37**	.47**	−.46**	.56**	.17**	.04NS
	Self-Management Experiences	.29**	.47**	.42**	.40**	−.54**	.37**	.19*	−.04NS
	Family Conflict	.37**	.37**	.31**	.44**	−.43**	.46**	.12NS	−.09NS
12-17	Total	.56**	.76**	.65**	.61**	−.74**	.61**	.51**	−.25**
	Daily Emotional Experiences & Daily Activities	.48**	.74**	.63**	.52**	−.70**	.44**	.44**	−.14*
	Handling Diabetes Well	.52**	.53**	.44**	.61**	−.51**	.66**	.46**	−.31**
	Peer Relationships	.22**	.30**	.35**	.26**	−.34**	.44**	.24**	−.17**
	Family Relationships	.46**	.58**	.45**	.46**	−.61**	.51**	.41**	−.25**

Note. NS not significant. PedsQL = Pediatric Quality of Life Inventory; SWLS = Satisfaction with Life Scale; PAID = Problem Areas in Diabetes scale; DSTAR = Diabetes Strengths and Resilience measure; SCI = Self-Care Inventory; HbA1c = hemoglobin A1c. Parents completed the SCI about children ages 8–11.

* $p < .05$; ** $p < .01$.

As with all clinical research, there are limitations of this research to consider. The formative qualitative interviews that laid the foundation for the T1DAL assessments took place with participants from one tertiary academic medical center located in a large city in the Southwestern United States. This may limit the generalizability to other regions. However, the sample's racial/ethnic diversity, the consistency of the findings with published literature about the experiences of youth with T1D, and the recruitment of participants from other locations in later phases of the study minimize this concern. Another limitation is that the measures do not assess HRQOL issues related the use of technologies in diabetes management. Given the current rapid pace of development of diabetes management technologies, we were concerned that including items related to devices may render the measures obsolete. Other measures that assess behavioral issues related to technologies (e.g., Diabetes Technology Questionnaire for continuous glucose monitoring, Wysocki, Reeves, Kummer, Ross, & Yu, 2015; INSPIRE measures for automated insulin delivery, Weissberg-Benchell et al., 2019) may be more relevant and could be used in conjunction with T1DAL. Finally, the Fleisch-Kincaid Grade Level calculations (based on word and sentence length) for each measure are around 6th–7th grade. Although these ratings suggest the language may be above the reading level of some children, the estimates may be inflated due to the frequent inclusion of the multisyllabic word “diabetes.” Our rigorous approach to ensure developmental appropriateness limits this concern, including using simple language and sentence structure in the measure development process, testing the measures and obtaining feedback from multiple sets of youth in the target age-ranges, and making adjustments to the wording based on their suggestions.

Conclusions

This work adds value to the field by providing a well-validated set of measures that are developmentally tailored and that can be used from childhood through adolescence. In a critical review of diabetes-specific HRQOL instruments and practical guide to improving HRQOL assessment, Fisher et al. (2016) noted that instruments are often selected because they are commonly used, whether or not they precisely measure the desired construct. To address this problem, the T1DAL measures provide a new option for assessing diabetes-specific HRQOL in youth that relies on a broader conceptualization than has often been used in the past. Our approach includes both positive and negative aspects of living with diabetes and reflects issues and concerns that are specific to childhood and adolescence.

A multidisciplinary study team developed, tested, and analyzed the measures separately for each age-band, resulting in developmentally specific scales and items. Because qualitative data from youth with T1D informed the new T1DAL measures for children and adolescents, the item and factors within each measure reflect the different realities of living with T1D in these two developmental periods (Levi & Drotar, 1998). For example, with respect to the roles of family and other people in HRQOL, the differences in items for children and adolescents reflect more extensive family involvement in managing diabetes during childhood and widening social circles of influence during adolescence. The consistent scoring across ages permits comparison of scores within each age-band and longitudinal assessment of diabetes-specific HRQOL over time for research and clinical care.

Another unique aspect of the T1DAL measures that reflects the voices of children and adolescents with T1D is the inclusion of items that assess positive aspects of one's HRQOL. Other measures often

include only negative items, which reflect clinician-identified barriers to optimal glycemic outcomes and challenges to QOL. Emphasizing problems related to living with diabetes may result in inadvertently assessing other constructs, such as diabetes burden (Fisher et al., 2016); the T1DAL measures solve this problem by including items reflecting both problems and successes. The child and adolescent versions of the new T1DAL measures are valid in relation to measures of positive and negative constructs, including diabetes strengths and burden. With literature documenting the impact of psychosocial challenges on glycemic outcomes (Hagger, Hendrieckx, Sturt, Skinner, & Speight, 2016; Hood et al., 2014) and increasing awareness of the importance of diabetes-related strengths (Hilliard, Hagger, et al., 2017), this represents an important advance in HRQOL measurement.

Given previous research demonstrating the potential to improve HRQOL following assessment and clinical discussion of scores (de Wit et al., 2008), the T1DAL-Child and T1DAL-Adolescent measures have the potential to be used effectively as part of both clinical practice and research as a patient-reported outcome. The design and multistage testing of T1DAL within specific age-bands addresses the weaknesses of previous measures (Drotar et al., 1998b; de Wit et al., 2007). Their brevity makes them feasible to administer as part of a busy clinical practice or research protocol, and their developmental specificity with consistent scoring across age-bands makes them usable for longitudinal observations, which has not been easily attainable previously. Additional research is needed to test the T1DAL measures' sensitivity to change and to evaluate their utility to guide clinical conversations with healthcare providers.

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References

- Baars, R. M., Atherton, C. I., Koopman, H. I., Bullinger, M., Power, M., & the DISABKIDS group. (2005). The European DISABKIDS project: Development of seven condition-specific modules to measure health related quality of life in children and adolescents. *Health and Quality of Life Outcomes*, 3, 70–78.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77–101.
- Cao, V. T., Eshtehardi, S. S., McKinney, B. M., Anderson, B., Marrero, D. G., Thompson, D., & Hilliard, M. E. (2018). What is health-related quality of life? Perspectives from diabetes care providers. *Diabetes*, 67(Suppl 25), 848.
- Centers for Disease Control and Prevention. (2019). *Child development: Positive parenting*. Retrieved from <https://www.cdc.gov/ncbddd/childdevelopment/positiveparenting/index.html>.
- Chaplin, J. E., Hallman, M., Nilsson, N. O., & Lindblad, B. (2012). The reliability of the disabled children's quality-of-life questionnaire in Swedish children with diabetes. *Acta Paediatrica*, 101, 501–506.
- de Wit, M., Delemarre-van de Waal, H. A., Bokma, J. A., Haasnoot, K., Houdijk, M. C., Gemke, R. J., & Snoek, F. J. (2008). Monitoring and discussing health-related quality of life in adolescents with type 1 diabetes improves psychosocial well-being: A randomized controlled trial. *Diabetes Care*, 31, 1521–1526.
- de Wit, M., Delemarre-van de Waal, H. A., Pouwer, F., Gemke, R. J., & Snoek, F. J. (2007). Monitoring health related quality of life in adolescents with diabetes: A review of measures. *Archives of Disease in Childhood*, 92, 434–439.
- de Wit, M., Winterdijk, P., Aanstoot, H.-J., Anderson, B., Danne, T., Deeb, L., ... Snoek, F. (2012). Assessing diabetes-related quality of life of youth with type 1 diabetes in routine clinical care: The MIND-Youth Questionnaire (MY-Q). *Pediatric Diabetes*, 13, 638–646.
- Delamater, A. M., de Wit, M., McDarby, V., Malik, J. A., Hilliard, M. E., Northam, E., & Acerini, C. L. (2018). ISPAD clinical practice consensus guidelines 2018: Psychological care of children and adolescents with type 1 diabetes. *Pediatric Diabetes*, 19(Suppl 27), 237–249.
- Diener, E., Emmons, R. A., Larsen, R. J., & Griffin, S. (1985). The satisfaction with life scale. *Journal of Personality Assessment*, 49, 71–75.
- Drotar, D., Levi, R., Palermo, T. M., Riekert, K. A., Robinson, J. R., & Walders, N. (1998a). Clinical applications of health-related quality of life assessment for children and adolescents. In D. Drotar (Ed.), *Measuring health-related quality of life in children and adolescents: Implications for research and practice* (pp. 329–340). Mahwah, NJ: Lawrence Erlbaum Associates.
- Drotar, D., Levi, R., Palermo, T. M., Riekert, K. A., Robinson, J. R., & Walders, N. (1998b). Recommendations for research concerning the measurement of pediatric health-related quality of life. In D. Drotar (Ed.), *Measuring health-related quality of life in children and adolescents: Implications for research and practice* (pp. 341–349). Mahwah, NJ: Lawrence Erlbaum Associates.
- Eshtehardi, S. S., Cao, V. T., Anderson, B. J., McKinney, B. M., Marrero, D. G., & Hilliard, M. E. (2017a). The “helping dilemma”: Experiences of parents and partners of

- people with type 1 diabetes (T1D) across the lifespan. *Diabetes*, 66, 871.
- Eshtehardi, S. S., Cao, V. T., Anderson, B. J., Marrero, D., Thompson, D., & Hilliard, M. E. (2017b). Characterizing diabetes burnout in parents of youth with type 1 diabetes (T1D). *Pediatric Diabetes*, 18, 02.
- Eshtehardi, S. S., Cao, V. T., McKinney, B. M., Anderson, B. J., Marrero, D. G., & Hilliard, M. E. (2017c). *Money talks: Financial aspects of type 1 diabetes and parental quality of life*. Poster presented at Society of Pediatric Psychology Annual Conference, Portland, OR.
- Eshtehardi, S. S., Cao, V. T., McKinney, B. M., Anderson, B. J., Marrero, D. G., Thompson, D. I., & Hilliard, M. E. (2018). *Youth and parent feelings about type 1 diabetes management technologies*. Poster session presented at The Society of Pediatric Psychology Annual Conference, Orlando, FL.
- Evans, M. A., Weil, L. E. G., Shapiro, J. B., Anderson, L. M., Vesco, A. T., Rychlik, K., ... Weissberg-Benchell, J. (2019). Psychometric properties of the parent and child problem areas in diabetes (PAID) measures. *Journal of Pediatric Psychology*, 44, 703–713.
- Fisher, L., Tang, T., & Polonsky, W. (2016). Assessing quality of life in diabetes: I. A practical guide to selecting the best instruments and using them wisely. *Diabetes Research and Clinical Practice*, 126, 278–285.
- Gonynor, C., Eshtehardi, S. S., Cao, V., McKinney, B. M., Anderson, B. J., Marrero, D. G., ... Hilliard, M. E. (2017). Food and eating behaviors among adolescents with type 1 diabetes and their parents. *Pediatric Diabetes*, 18, 272.
- Hagger, V., Hendrieckx, C., Sturt, S., Skinner, T. C., & Speight, J. (2016). Diabetes distress among adolescents with type 1 diabetes: A systematic review. *Current Diabetes Reports*, 16, 9.
- Hilliard, M. E., Eshtehardi, S. S., Cao, V. T., McKinney, B. M., Marrero, D. G., & Anderson, B. J. (2017). Life with type 1 diabetes (T1D) outside of clinic: Connecting online, in person, and through diabetes organizations. *Diabetes*, 66, 864.
- Hilliard, M. E., Hagger, V., Hendrieckx, C., Anderson, B. J., Trawley, S., Jack, M. M., ... Speight, J. (2017). Strengths, risk factors, and resilient outcomes in adolescents with type 1 diabetes: Results from Diabetes-MILES Youth Australia. *Diabetes Care*, 40, 849–855.
- Hilliard, M. E., Iturralde, E., Weissberg-Benchell, J., & Hood, K. K. (2017). The diabetes strengths and resilience measure for adolescents with type 1 diabetes (DSTAR-Teen): Validation of a new, brief self-report measure. *Journal of Pediatric Psychology*, 42, 995–1005.
- Hilliard, M. E., Kushner, J. A., Hood, K. K., Weissberg-Benchell, J., & Anderson, B. J. (2015). Psychometric properties of a measure for preadolescents with type 1 diabetes. *Diabetes*, 64(Suppl 1), 845.
- Hilliard, M. E., Mann, K. A., Peugh, J. L., & Hood, K. K. (2013). How poorer quality of life in adolescence predicts subsequent type 1 diabetes management and control. *Patient Education and Counseling*, 91, 120–125.
- Hoey, H., Aanstoet, H.-J., Chiarelli, F., Daneman, D., Danne, T., Dorchy, H., ... Aman, J. (2001). Good metabolic control is associated with better quality of life in 2, 101 adolescents with type 1 diabetes. *Diabetes Care*, 24, 1923–1928.
- Holmbeck, G. N., & Devine, K. A. (2009). Editorial: An author's checklist for measure development and validation manuscripts. *Journal of Pediatric Psychology*, 34, 691–696.
- Hood, K. K., Beavers, D. P., Yi-Frazier, J., Bell, R., Dabelea, D., Mckeown, R. E., & Lawrence, J. M. (2014). Psychosocial burden and glycemic control during the first 6 years of diabetes: Results from the SEARCH for diabetes in youth study. *Journal of Adolescent Health*, 55, 498–504.
- Ingersoll, G. M., & Marrero, D. G. (1991). A modified quality-of-life measure for youths: Psychometric properties. *The Diabetes Educator*, 17, 114–118.
- Jaser, S. S. (2011). Family interaction in pediatric diabetes. *Current Diabetes Reports*, 11, 480–485.
- Levi, R., & Drotar, D. (1998). Critical issues and needs in health-related quality of life assessment of children and adolescents. In D. Drotar (Ed.), *Measuring health-related quality of life in children and adolescents: Implications for research and practice* (pp. 3–24). Mahwah, NJ: Lawrence Erlbaum Associates.
- Lewin, A. B., LaGreca, A. M., Geffken, G. R., Williams, L. B., Duke, D. C., Storch, E. A., & Silverstein, J. H. (2009). Validity and reliability of an adolescent and parent rating scale of type 1 diabetes adherence behaviors: The self-care inventory (SCI). *Journal of Pediatric Psychology*, 34, 999–1007.
- Lohr, K. N., & Zebrack, B. J. (2009). Using patient-reported outcomes in clinical practice: Challenges and opportunities. *Quality of Life Research*, 18, 99–107.
- McMillan, C. V., Honeyford, R. J., Datta, J., Madge, N. J., & Bradley, C. (2004). The development of a new measure of quality of life for young people with diabetes mellitus: The ADDQoL-Teen. *Health and Quality of Life Outcomes*, 2, 61.
- Nansel, T. R., Weissberg-Benchell, J., Wysocki, T., Laffel, L., & Anderson, B. & Steering Committee of the Family Management of Diabetes Study. (2008). Quality of life in children with type 1 diabetes: A comparison of general and diabetes-specific measures, and support for a unitary diabetes quality of life construct. *Diabetic Medicine*, 25, 1316–1323.
- Peters, A., & Laffel, L. (2013). *The American Diabetes Association/JDRF Type 1 Diabetes Sourcebook*. Alexandria, VA: American Diabetes Association.
- Pihlaskari, A., Anderson, B. J., Eshtehardi, S. S., McKinney, B. M., Marrero, D. G., & Hilliard, M. E. (2017). *Diabetes disclosure and support-seeking styles in adolescents and young adults with type 1 diabetes*. Poster session presented at the meeting of The Society of Pediatric Psychology Annual Conference, Portland, OR.
- Ravens-Sieberer, U., & Bullinger, M. (2001). Quality of life from a patient group perspective. In H.M. Koot & J.L. Wallander (Eds.), *Quality of Life in Child and Adolescent Illness: Concepts, Methods and Findings*. (pp. 151–179). New York, NY: Taylor & Francis, Inc.
- Speight, J., Reaney, M. D., & Barnard, K. D. (2009). Not all roads lead to Rome: A review of quality of life measurement in adults with diabetes. *Diabetic Medicine*, 26, 315–327.

- Tang, T. S., Yusuf, F. L. A., Polonsky, W. H., & Fisher, F. (2017). Assessing quality of life in diabetes: II - Deconstructing measures into a simple framework. *Diabetes Research and Clinical Practice*, 126, 286–302.
- Varni, J. W., Delamater, A. M., Hood, K. K., Raymond, J. K., Chang, N. T., Driscoll, K. A., ... Pediatric Quality of Life Inventory 3.2 Diabetes Module Testing Study Consortium. (2018). PedsQL 3.2 Diabetes Module for children, adolescents, and young adults: Reliability and validity in type 1 diabetes. *Diabetes Care*, 41, 2064–2071.
- Varni, J. W., Seid, M., & Kurtin, P. S. (2001). PedsQL 4.0: reliability and validity of the Pediatric Quality of Life Inventory version 4.0 generic core scales in healthy and patient populations. *Medical Care*, 39, 800–812.
- Wallander, J. L., Schmitt, M., & Koot, H. M. (2001). Quality of life measurement in children and adolescents: Issues, instruments, and applications. *Journal of Clinical Psychology*, 57, 571–585.
- Wasserman, R. M., Eshtehardi, S. S., Cao, V. T., Anderson, B. J., Marrero, D. G., McKinney, M. B., & Hilliard, M. E. (2017). Developmental shifts in worries about life with type 1 diabetes (T1D) from childhood through young adulthood. *Diabetes*, 66, 868.
- Weissberg-Benchell, J., & Antisdel-Lomaglio, J. (2011). Diabetes-specific emotional distress among adolescents: Feasibility, reliability, and validity of the problem areas in diabetes-teen version. *Pediatric Diabetes*, 12, 341–344.
- Weissberg-Benchell, J., Shapiro, J. B., Hood, K., Laffel, L. M., Naranjo, D., Miller, K., & Barnard, K. (2019). Assessing patient-reported outcomes for automated insulin delivery systems: The psychometric properties of the INSPIRE measures. *Diabetic Medicine*, 36, 644–652.
- Wu, Y., Thompson, D., Aroian, K. J., McQuaid, E. L., & Deatrick, J. A. (2016). Commentary: Writing and evaluating qualitative research reports. *Journal of Pediatric Psychology*, 41, 493–505.
- Wysocki, T., Reeves, G., Kummer, K., Ross, J., & Yu, M. (2015). Psychometric validation of the Diabetes Technology Questionnaire. *Diabetes*, 26, 729–735.
- Young-Hyman, D., de Groot, M., Hill-Briggs, F., Gonzalez, J. S., Hood, K., & Peyrot, M. (2016). Psychosocial care for people with diabetes: A position statement of the American Diabetes Association. *Diabetes Care*, 39, 2126–2140.