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Health-Related Quality of Life in Parents and Partners of People with Type 1 Diabetes: Development and Validation of Type 1 Diabetes and Life (T1DAL) Measures

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Abstract

Introduction: Despite the significant impact of type 1 diabetes (T1D) on family, few instruments are available to assess health-related quality of life (HRQOL) among family members of people with T1D. This study aimed to develop and evaluate the psychometric properties of new measures of diabetes-specific HRQOL for parents and partners of people with T1D. We report on the multi-step development and validation process for the self-report Type 1 Diabetes and Life (T1DAL) measures, with versions for parents of youth age <8, 8–11, 12–17, and 18–25 years, and for partners of people age ≥ 18 years with T1D.

Method: First, we conducted qualitative interviews (total parents/partners n=38) to develop draft measures and piloted them (total n=20). Next, we tested the measures' psychometric properties. Participants (total across versions n=813) at six T1D Exchange Clinic Network sites completed the appropriate T1DAL measure and validated measures of related constructs. We then reduced each T1DAL measure to 20–30 items in length based on psychometric data and participant feedback. Eleven participants reviewed the final measures via cognitive debriefing.

Results: The T1DAL measures for parents and partners demonstrated good internal consistency ($\alpha=0.80-0.88$) and test-retest reliability ($r=0.73-0.86$). Correlations with measures of general quality of life, generic and diabetes-specific HRQOL, and diabetes burden demonstrated construct validity. Factor analyses identified 3–4 subscales/measure. Participants reported being satisfied with the shortened measures, which took 5–10 minutes to complete.

Discussion: The new T1DAL measures for parents and partners of people with T1D are reliable, valid, and ready for use in research and clinical settings.

Keywords

Patient-reported Outcomes; Quality of life; Psychosocial; Assessment; Family

Patient-reported outcomes are important to assess and report in clinical trials and patient care (Lohr & Zebrack, 2009), especially for people with chronic conditions including type 1 diabetes (T1D) (Agiostatidou et al., 2017). Professional diabetes organizations (Agiostatidou et al., 2017; American Diabetes Association, 2020; Delamater et al., 2018; Young-Hyman et al., 2016) recommend routinely monitoring health-related quality of life (HRQOL), one's well-being related to health, physical abilities, social-emotional functioning, and satisfaction with healthcare (El Achhab et al., 2008; Levi & Drotar, 1998; Speight et al., 2019). Psychometrically sound, clinically relevant measures are necessary to assess T1D-specific HRQOL. Most existing T1D-specific HRQOL measures are for youth with T1D, with fewer measures available for adults with T1D. Our team addressed this need by developing and validating the Type 1 Diabetes and Life (T1DAL) measures, new measures of T1D-specific HRQOL for children, adolescents, and adults with T1D (Hilliard et al., 2020a, 2020b).

Research with parents and partners of people with T1D suggests having a loved one with diabetes may influence many domains of HRQOL, including T1D-related distress, worry, sleep, and symptoms of depression and anxiety (Jaser et al., 2017; Polonsky et al., 2016; Whittemore, et al., 2012). Moreover, parents and partners' experiences are linked with their family members' self-management behaviors and glycemic outcomes (Polonsky et al., 2016; Whittemore et al., 2012). Thus, accurate measurement of T1D-related HRQOL in parents and partners is valuable for diabetes care and research.

There are two available instruments to measure HRQOL in parents of youth with T1D, each with limitations. The 37-item Parents Diabetes Quality of Life Questionnaire (PDQLQ; Vandagriff et al., 1992) was modified from an HRQOL measure for adults with T1D (i.e., language changed to refer to parent rather than person with T1D); psychometric data from 93 parents of youth age 3–20 included only internal reliability coefficients for the total score and three subscales not confirmed via factor analysis. The 37-item Well-Being and Satisfaction of Caregivers of Children with Diabetes Questionnaire (WE-CARE; Cappelleri et al., 2008) was developed by a pharmaceutical company with input from pediatricians, youth, and parents. Psychometric data from 116 parents of children age 6–11 indicated internal reliability and validity compared to two measures of generic HRQOL, with four factors derived from factor analysis (three focused on issues related to insulin administration). Other T1D-specific HRQOL measures involve parents only as proxy-reporters about their children's HRQOL and do not measure parents' own HRQOL (Varni et al., 2018). There are no T1D-specific HRQOL measures for partners of adults with T1D. Validated measures assess constructs related to but conceptually different from parents' or partners' T1D-specific HRQOL, such as pediatric parenting stress (Streisand et al., 2001), diabetes-related distress (Evans et al., 2019; Polonsky et al., 2016), fear of hypoglycemia (Patton et al., 2008), and impact of diabetes on the family (Katz et al., 2015). While these are valuable for measuring specific concerns faced by parents and partners, drawing conclusions about HRQOL from these measures can be misleading (Fisher et al., 2017).

Taken together, the few available instruments for use with parents and partners of people with T1D have limitations including incomplete psychometric data from studies with relatively small samples, restricted age ranges for parents of youth with T1D, and few options for partners of adults with T1D. The measures do not assess all domains that comprise T1D-specific HRQOL, may be outdated, and largely query only the negative aspects of being a parent or partner of someone with T1D. Given these concerns, new measures for use in clinical care and research settings are warranted.

To fill this gap, we designed and tested the psychometric properties of the new T1DAL measures for parents and partners of people with T1D in five age-bands (Parents of: Young Children, age <8; Children, age 8–11; Adolescents, age 12–17; Young Adults, age 18–25; and Partners of Adults, age 18+). This was part of a broader initiative to develop a suite of T1D-specific HRQOL measures for people with T1D across the lifespan and their family members, with the goal of introducing reliable, valid tools that would be brief, relevant to clinical care, and appropriate across developmental stages. We report the validity and

reliability of each T1DAL measure, as well as subscales for each measure derived from factor analysis.

Methods

We used a three-phase approach to develop and validate the T1DAL measures for parents and partners, per measure development guidelines (Drotar et al., 1998b; Holmbeck & Devine, 2009). In Phase 1 we created, pilot tested, and refined the measures based on qualitative data from parents and partners of people with T1D and review of the literature and existing measures. In Phase 2 we evaluated the reliability, validity, and factor structure of the new measures, and reduced the number of items. In Phase 3 we conducted a final review and obtained comments about the measures from participants. A flow chart (Figure 1) outlines the study phases, sample size in each phase, and number of items per measure in each phase.

In each phase, inclusion criteria for parents and partners were age ≥ 18 years, parent of someone ≥ 25 or partner of someone ≥ 18 years with T1D (duration ≥ 12 months), and fluent in written/spoken English. Significant comorbid medical, cognitive, or mental health conditions that could interfere with ability to consent/participate were exclusions. Study staff followed informed consent procedures including describing the study, confirming understanding, answering questions, and obtaining written documentation of consent. We offered small monetary incentives for participation. Each phase was approved by the appropriate institutional review board(s).

Recruitment

Phase 1: We recruited parents of youth and young adults with T1D and partners of adults with T1D to complete qualitative interviews to inform item content. Research staff recruited participants at diabetes clinics at Texas Children's Hospital (Houston, TX) and Indiana University School of Medicine (Indianapolis, IN). Staff reviewed clinic schedules to identify potentially eligible families, then mailed informational letters with an option to opt-out of further contact. Staff followed up by telephone and in-person at a T1D clinic visit to obtain written informed consent. Qualitative interviews took place at that time or a follow-up appointment. In total, 25 parents and 13 partners consented and completed the interview. After drafting the T1DAL measures, staff recruited 13 new parents and 7 new partners to pilot the measures and provide feedback. Table 1 summarizes participant characteristics.

Phase 2: Recruitment took place at six sites in the T1D Exchange Clinic Network (investigators and staff from each site listed in online Supplement 4). At each site, study staff identified potentially eligible families via review of clinic schedules. We prioritized recruiting participants already affiliated with the T1D Exchange Clinic Registry to access demographic data. Staff mailed letters and/or met with potentially eligible families at clinic visits to introduce the study and enroll participants. After providing informed consent, participants completed questionnaires on two occasions and granted access to medical charts and Clinic Registry data. In total, 900 parents and partners enrolled and 813 (90%) had calculable T1DAL scores. Table 1 lists the number with calculable T1DAL scores in each age-band.

Phase 3: The PI posted on Twitter to recruit a new sample of 2–3 participants per age-band to conduct a final review and obtain feedback about the measures. People interested in participating contacted us and study staff described the study, confirmed eligibility, and obtained informed consent. We enrolled 11 people (Table 1).

Procedures

Phase 1: The research team generated a list of HRQOL-related issues to consider including in the measures based on literature review and clinical experience. To gather perspectives of parents and partners with a family member with T1D, we completed qualitative interviews (individual or small focus groups). Staff used semi-structured scripts that included open-ended questions and prompts/probes for clarification, which addressed a wide range of HRQOL topics (see online Supplement 1). Staff invited participants to discuss any other issues relevant to their quality of life. We audio-recorded the interviews and had them professionally transcribed. We obtained medical and demographic data via questionnaire and medical chart review.

The research team drafted the T1DAL measures using the themes identified in the qualitative interviews, topics from the literature, and investigators' clinical experiences. The format was based on the Mind Youth-Questionnaire (de Wit et al., 2012). Research team members with behavioral and medical expertise in diabetes reviewed the items. Next, we pilot tested the draft measures and conducted cognitive debriefing (see online Supplement 2) in a new sample: 20 participants completed the measures, then the interviewer asked them to specify any items they felt were repetitive, confusing, or unimportant, indicate any items that made them uncomfortable, rate how hard or easy it was to answer each item, describe how they interpreted specific words/phrases, make recommendations for clarification, and suggest any additional topics related to living with T1D. Staff asked participants how they would feel about completing the questionnaire at their child's/partner's T1D appointments. The study team reviewed professional transcriptions of the interviews and interviewers' summary notes to revise items.

Phase 2: At enrollment and 1–2 months later, 813 participants completed questionnaires via emailed link to a secure web-based portal or paper questionnaires if preferred. Study staff obtained medical and demographic data via electronic medical record review.

Phase 3: Study staff emailed the T1DAL measure for their respondent type/age-band and asked 11 participants to time themselves while completing it. We then conducted cognitive interviews by phone to seek feedback about clarity, appropriateness, and redundancy (similar to Phase 1). Staff recorded, professionally transcribed, and made summary notes about the interviews. Experts on the study team also reviewed and commented on the shortened versions of the T1DAL. The principal investigators used participant and collaborator feedback to finalize measures.

Measures (Phase 2)

Participants (n=813) completed the age-appropriate T1DAL measure and validated measures of related constructs at baseline. Participants completed the T1DAL measure again at follow-up to examine test-retest reliability.

T1DAL Measures—Participants answered each item using a 5-point Likert scale (‘Completely Disagree’ to ‘Completely Agree’) based on their experiences over the previous 4 weeks. Participants could indicate items that were not applicable. Items were grouped into categories (e.g., “Diabetes and How I Feel,” “Diabetes and Our Family”). Positively-worded items were scored: 0=0, 1=25, 2=50, 3=75, or 4=100, negatively-worded items were reverse-scored. We calculated subscale and total scores by computing the mean and multiplying by 25 to convert to a 0–100 point scale, with higher scores representing better HRQOL. Having the same scoring across measures permits users to compare individual scores or group means both within and across age-bands over time. Smaller samples of partners for each adult age-band required that the final product applies to partners of adults of all ages. To avoid over-interpreting individual items, we did not calculate scores if >10% of items were not answered (>1 missing item for subscales, >3 missing items for total). Table 2 summarizes the number of items in the measures used in the validation study.

Construct Validity

General quality of life: Participants completed the 5-item Satisfaction with Life Scale (SWLS) (Diener et al., 1985) by rating their agreement with each sentence (1 “Strongly Disagree” to 7 “Strongly Agree”). The α range in this sample was 0.89–0.92.

Generic HRQOL: Participants completed the 12-item Short Form Health Survey, Version 2 (SF-12) (Ware et al., 1996), answering questions about their physical and mental health symptoms and their general health. We calculated the Mental Health Composite Score (MCS) for use in validity analyses. The α range in this sample was 0.15–0.41.

Diabetes-related burden: Parents of youth <age 12 completed the 18-item Problem Areas in Diabetes-Parent Survey Revised (PAID-PR; Markowitz et al., 2011), and parents of youth age 12–17 completed the 26-item Problem Areas in Diabetes – Parent of Teen version (P-PAID-T; Weissberg-Benchell & Antisdel-Lomaglio, 2011) (α range = 0.90–0.97). Partners completed the 21-item Diabetes Distress Scale-Partner (DDS-P; α range = 0.94–0.95) (Polonsky et al., 2016), assessing the degree to which they experienced distress related to their family member’s T1D. We modified the DDS-P for parents of young adults (age 18–25) to refer to their child instead of partner. Parents of youth <age 18 also completed the 15-item Diabetes Family Impact Scale (DFIS, α range = 0.81–0.87) (Katz et al., 2015), assessing how T1D affected school, work, finances, and parents’ well-being.

Criterion Validity Measures

Diabetes self-management/adherence: Parents of youth <age 12 completed a parent-proxy version of the 15-item Self-Care Inventory-Revised (Lewin et al., 2009). The α range in this sample was 0.89–0.91. Because older youth and adults complete much of their T1D self-management away from parents/partners, we did not collect proxy report over age 12.

Glycemic control: We extracted the HbA1c value closest to the date of study participation from the medical record of each participant's child/partner with T1D.

Analytic Plan

Phase 1: To identify HRQOL-related themes from the qualitative interviews, we conducted hybrid thematic analysis of the transcripts (Braun & Clarke, 2008; Fereday & Muir-Cochrane, 2006) using NVIVO software (Version 11) and following qualitative analysis guidelines (Wu et al., 2016). Three behavioral scientists with expertise in T1D and three research staff read transcripts, identified recurring concepts, and developed a codebook with operational definitions. Staff applied the codebook to the transcripts and brought any additional concepts they observed to the team for discussion. New codes were defined, added to the codebook, and applied to all transcripts. This recursive process continued until we found no new codes and all transcripts were coded. Staff double-coded 25% of transcripts and resolved any differences. For the cognitive interviews, staff took detailed notes of participant feedback, and PIs reviewed the comments to revise measures.

Phase 2: We analyzed data separately for each respondent type (parent/partner) and age-band. For each measure, we conducted exploratory factor analyses with all administered items, using squared multiple correlations as prior communality estimates. We extracted factors using maximum likelihood and promax (oblique) rotation. To determine the number of factors for each version, we examined scree plots and proportion of variance explained, and considered clinical interpretability and meaningfulness of each solution. To shorten the measures to around 20–30 items, we inspected item properties and used decision rules: no change in α if item dropped, 85% response rate, and no ceiling or floor effect. All items were required to have a significant factor loading (> 0.30) on at least one factor; for items loading on > 1 factor, we considered the size of each loading and conceptual fit with each factor. We omitted items that assessed other constructs (e.g., self-management), were repetitive, or that received negative comments during cognitive debriefing.

To determine reliability (internal consistency), we calculated Cronbach's α . Internal consistency measures the degree to which items within a measure correlate with one another, and is commonly accepted at $\alpha > 0.70$ (Taber, 2018). To determine validity, we calculated Pearson's correlations with the other measures. To determine test-retest reliability, we calculated Pearson's correlations across timepoints. For correlations, we use a significance level of $p < 0.05$.

Results

Phase 1:

We reported themes related to HRQOL in parents/partners of someone with T1D elsewhere (Eshtehardi et al., 2017a, 2017b; Gonynor et al., 2017; Hilliard et al., 2017; Wasserman et al., 2017). We modified the measures based on comments from cognitive debriefing (e.g., removing confusing or redundant items, adding instructions for clarification).

Phase 2:

Table 2 presents the preliminary data from the factor analyses for each age-band, and Table 3 presents the number of items, readability, subscale names, mean scores, and reliability results for each final measure post-factor analysis. Cronbach's α was between 0.80–0.88 for the total scores. Table 4 presents descriptive statistics for each validation measure, and Table 5 presents TIDAL validity data. Total scores and most subscale scores for each age-band were significantly correlated with the construct validity measures of general quality of life, generic HRQOL, and diabetes-related burden. Associations of total and subscale scores with criterion validity measures (i.e., measures of diabetes management/adherence and HbA1c of the respondent's child or partner with diabetes) were mixed. Online Supplement 3 provides example items for each measure.

Phase 3:

Parents/partners said the measures were easy and comfortable to answer and took <10 minutes. The measures demonstrated good face validity. Participants felt the measures were clear, comprehensive, and appropriately assessed topics relevant to their experiences with T1D. No changes were made to the measures based on this feedback.

Discussion

Psychometric data support the validity, reliability, and utility of the newly developed TIDAL measures for assessing HRQOL in parents and partners of people with T1D. Unlike other measures that rely on family members for proxy-reports of the HRQOL of their children/partners with T1D, the purpose of TIDAL is to assess the parents' and partners' own experiences. Using rigorous measurement development methods, we designed the measures with qualitative and quantitative data from parents and partners of people with T1D across the lifespan, and evaluated their psychometric properties in large geographically diverse samples.

The parent and partner TIDAL measures had strong psychometric properties, as evidenced by consistent significant associations with validity measures, high internal consistency, and significant test-retest reliability coefficients for the total score. These patterns were also evident for the subscales, which were identified via individual factor analyses for each measure. The construct validity data show the total score and most subscale scores accurately captured positive and negative aspects of T1D-specific HRQOL in parents and partners, including general quality of life, generic HRQOL, diabetes-related distress, and family impact of diabetes.

Results were mixed for criterion validity. Partner scores were significantly, negatively correlated with partners' HbA1c as expected, while most parent TIDAL scores were not correlated with children's HbA1c. This finding does not diminish the importance of parents' HRQOL. Rather, it suggests that unlike youth whose experiences living with T1D are directly linked with the physical, emotional, and other aspects of their own glycemic management and variability (Hilliard et al., 2020), parents' HRQOL may be less influenced by glycemia and more by management demands, family interactions, and safety concerns.

A parental HRQOL-HbA1c link may be positive or negative: the effort required to achieve low HbA1c may take a toll on HRQOL, and worries related to a high HbA1c may also relate to poorer HRQOL. Conversely, as adults with T1D may require less tangible diabetes management assistance from partners, this HRQOL-HbA1c link may be weaker. Moreover, aspects of HRQOL including greater marital satisfaction and having an engaged partner have been linked to lower HbA1c (Trief et al., 2017). Additionally, T1DAL total scores were correlated with parent-reported adherence in the age 8–11 group but not <age 8, perhaps reflecting the challenges associated with caring for young children with T1D irrespective of HbA1c (Streisand & Monaghan, 2015). Parents' well-being may have more to do with T1D management demands as children get older and assume more responsibility for T1D management tasks.

The total score alphas indicated good internal consistency, and subscale scores were good-fair. Lower internal consistency of some subscales was likely attributable to having fewer items per factor; this was intentional, as we prioritized brevity and minimizing redundancy between items. Significant test-retest reliability for all total and subscale scores demonstrated the measures' stability. Together, these psychometric data support the parent and partner T1DAL measures being appropriate for use and represent an advance beyond the limited psychometrics published about previous measures. However, use caution to avoid use/over-interpretation of individual subscales for research.

The parent and partner T1DAL measures assess T1D-specific HRQOL across the lifespan. We designed and validated the measure for parents of youth in different age-bands (age 5–25) separately with the goal of having measures that would be relevant as parents' experiences/responsibilities shift with the aging of their children. This developmental stage approach ensured that each measure reflected the specific HRQOL-related issues relevant to each period of childhood (Levi & Drotar, 1998). All T1DAL versions are scored on a 1–100 scale, which facilitates comparison within and across age-bands over time. Smaller samples of partners for each adult age-band required that the final product applies to partners of adults of all ages.

The results from use of the T1DAL measures have implications for clinical practice. Parents and partners in Phase 2 had total scores around 60 out of 100, indicating moderate T1D-specific HRQOL. Previous studies have targeted youths' HRQOL by integrating assessment responses into T1D care visits (de Wit et al., 2008); the new T1DAL measures for parents and partners offer the possibility of offering similar clinic-integrated family support. Most family-focused behavioral interventions in T1D teach parents skills to improve children's T1D outcomes (Lohan et al., 2015; McBroom & Enriquez, 2009) or aim to enhance partners' support in adults with type 2 diabetes (Trief et al., 2016). Tailored parent/partner interventions for T1D based on their HRQOL experiences would help to advance the field.

There are limitations to consider. Phase 1 qualitative interviews took place at two academic medical centers in urban areas of the United States, and parents in all phases tended to be mothers (partners were more evenly split between males and females). These characteristics of our sample may limit generalizability somewhat. However, the racial/ethnic and socio-economic diversity across phases and sampling at large clinical centers serving urban,

suburban, and rural communities across the U.S. in the validation study (Phase 2) enhance generalizability. Although use of new diabetes technologies impacts parents/partners of people with T1D (Hilliard et al., 2019a, Barnard et al., 2016), T1DAL measures do not include items about device use. Because technology evolves quickly, we did not want the measures to become outdated; we recommend pairing T1DAL with measures designed to specifically address experiences with technology, such as the Diabetes Technology Questionnaire for continuous glucose monitoring (Wysocki et al., 2015) and the INSPIRE measures for automated insulin delivery (Weissberg-Benchell et al., 2019). Finally, we tested reliability, validity, and factor structure, but did not evaluate sensitivity to intervention.

The new T1DAL measures for assessing HRQOL in parents and partners of people with T1D across the lifespan have been validated using rigorous instrument design methods and address the gaps of existing measures. They are brief and clinically relevant, making them appropriate to use in research and practice. The measures cover the lifespan, facilitating longitudinal assessment, and can be used for individual- and family-based interventions to improve HRQOL.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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REFERENCES

- Agiostatridou G, Anhalt H, Ball D, Blonde L, Gourgari E, Harriman KN, ...Weinzimer SA (2017). Standardizing clinically meaningful outcome measures beyond HbA1c for type 1 diabetes: A consensus report of the American Association of Clinical Endocrinologists, the American Association of Diabetes Educators, the American Diabetes Association, the Endocrine Society, JDRF International, The Leona M. and Harry B. Helmsley Charitable Trust, the Pediatric Endocrine Society, and the T1D Exchange. *Diabetes Care*, 40, 1622–1630. doi: 10.2337/dc08-0394 [PubMed: 29162582]
- American Diabetes Association. (2019). 5. Facilitating behavior change and well-being to improve health outcomes: Standards of medical care in diabetes—2020. *Diabetes Care*, 43(Suppl 1), S48–S65. doi: 10.2337/dc20-S005
- Barnard K, Crabtree V, Adolfsson P, Davies M, Kerr D, Kraus A, ...Serbedzija G (2016). Impact of type 1 diabetes technology on family members/significant others of people with diabetes. *Journal Diabetes Science & Technology*, 10, 824–830. doi: 10.1177/1932296816645365

- Braun V, & Clarke V (2008). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77–101. doi: 10.1191/1478088706qp063oa
- Cappelleri JC, Gerber RA, Quattrin T, Deutschmann R, Luo X, Arbuckle R, & Abetz L (2008). Development and validation of the Well-being and Satisfaction of Caregivers of Children with Diabetes Questionnaire (WE-CARE). *Health and Quality of Life Outcomes*, 6, 3–11. doi:10.1186/1477-7525-6-3 [PubMed: 18205937]
- de Wit M, Delemarre-van de Waal HA, Bokma JA, Haasnoot K, Houdijk MC, Gemke RJ, & Snoek FJ (2008). Monitoring and discussing health-related quality of life in adolescents with type 1 diabetes improve psychosocial well-being: A randomized controlled trial. *Diabetes Care*, 31, 1521–1526. doi: 10.2337/dc08-0394 [PubMed: 18509204]
- de Wit M, Winterdijk P, Aanstoot HJ, Anderson B, Danne T, Deeb L, ...Snoek F; DAWN Youth Advisory Board. (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. doi: 10.1111/j.1399-5448.2012.00872.x [PubMed: 23173877]
- Delamater AM, de Wit M, McDarby V, Malik JA, Hilliard ME, Northam E, & Acerini CL (2018). ISPAD Clinical Practice Consensus Guidelines 2018: Psychological care of children and adolescents with type 1 diabetes. *Pediatric Diabetes*, 19(Suppl 27), 237–249. doi: 10.1111/pedi.12736 [PubMed: 30058247]
- Diener E, Emmons RA, Larsen RJ, Griffin S (1985). The Satisfaction with Life Scale. *Journal of Personality Assessment*, 49, 71–75. doi: 10.1207/s15327752jpa4901_13 [PubMed: 16367493]
- Drotar D, Levi R, Palermo TM, Riekert KA, Robinson JR, & Walders N (1998a). Clinical applications of health-related quality of life assessment for children and adolescents. In Drotar D (Ed.), *Measuring Health-Related Quality of Life in Children and Adolescents: Implications for Research and Practice* (pp. 329–340). Mahwah, New Jersey: Lawrence Erlbaum Associates.
- Drotar D, Levi R, Palermo TM, Riekert KA, Robinson JR, & Walders N (1998b). Recommendations for research concerning the measurement of pediatric health-related quality of life. In Drotar D (Ed.), *Measuring Health-Related Quality of Life in Children and Adolescents: Implications for Research and Practice* (pp. 341–349). Mahwah, New Jersey: Lawrence Erlbaum Associates.
- El Achhab Y, Nejjari C, Chikri M, & Lyoussi B (2008). Disease-specific health-related quality of life instruments among adults diabetic: A systematic review. *Diabetes Research and Clinical Practice*, 80, 171–184. doi: 10.1016/j.diabres.2007.12.020 [PubMed: 18279993]
- Eshtehardi SS, Cao VT, Anderson BJ, Marrero D, Thompson D, & Hilliard ME (2017a). Characterizing diabetes burnout in parents of youth with type 1 diabetes (T1D). *Pediatric Diabetes*, 18, 02.
- Eshtehardi SS, Cao VT, McKinney BM, Anderson BJ, Marrero DG, & Hilliard ME (2017b). The “helping dilemma”: Experiences of parents and partners of people with type 1 diabetes (T1D) across the lifespan. *Diabetes*, 66, 871.
- Evan MA, Weil LEG, Shapiro J, Anderson LM, Vesco A, 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. doi: 10.1093/jpepsy/jsz018 [PubMed: 30920628]
- Fereday J, & Muir-Cochrane E (2006). Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development. *International Journal of Qualitative Methods*, 5, 80–92. doi: 10.1177/160940690600500107
- Fisher L, Tang T, & Polonsky W (2017). 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. doi: 10.1016/j.diabres.2016.10.018 [PubMed: 28153545]
- Gonynor C, Eshtehardi SS, Cao V, McKinney BM, Anderson BJ, Marrero DG, ...Hilliard ME (2017). Food and eating behaviors among adolescents with type 1 diabetes and their parents. *Pediatric Diabetes*, 18, 272.
- Hilliard ME, Eshtehardi SS, Cao VT, McKinney BM, Marrero DG, & Anderson BJ (2017). Life with type 1 diabetes (T1D) outside of clinic: Connecting online, in person, and through diabetes organizations. *Diabetes*, 66, 864.
- Hilliard ME, Levy W, Anderson BJ, Whitehouse AL, Commissariat PV, Harrington KR, ...DiMeglio LA (2019a). Benefits and barriers of continuous glucose monitoring in young children with

type 1 diabetes. *Diabetes Technology & Therapeutics*, 21, 493–498. doi: 10.1089/dia.2019.0142 [PubMed: 31287721]

- Hilliard ME, Marrero DG, Minard CG, Cao VT, de Wit M, DuBose SN, ... Anderson BJ (2020a). Design and psychometrics for new measures of health-related quality of life in adults with type 1 diabetes: Type 1 Diabetes and Life (T1DAL). *Diabetes Research and Clinical Practice*, in press.
- Hilliard ME, Minard CG, Marrero D, de Wit M, Thompson D, DuBose SN, ... Anderson BJ (2020b). Assessing health-related quality of life in children and adolescents with diabetes: Development and psychometrics of the Type 1 Diabetes and Life (T1DAL) Measures. *Journal of Pediatric Psychology*, 45, 328–339. doi: 10.1093/jpepsy/jsz083 [PubMed: 31665389]
- Holmbeck GN, & Devine KA Editorial: An author's checklist for measure development and validation manuscripts. [Editorial]. (2009). *Journal of Pediatric Psychology*, 34, 691–696. doi: 10.1093/jpepsy/jsp046 [PubMed: 19487232]
- Jaser SS, Foster NC, Nelson BA, Kittelsrud JM, DiMeglio LA, Quinn M. ... Simmons JH; T1D Exchange Clinic Network. (2017). Sleep in children with type 1 diabetes and their parents in the T1D Exchange. *Sleep Medicine*, 39, 108–115. doi: 10.1016/j.sleep.2017.07.005 [PubMed: 29157581]
- Katz ML, Volkening LK, Dougher CE, & Laffel LM (2015). Validation of the Diabetes Family Impact Scale: A new measure of diabetes-specific family impact. *Diabetic Medicine*, 32, 1227–1231. doi: 10.1111/dme.12689 [PubMed: 25655562]
- Levi R, & Drotar D (1998). Critical issues and needs in health-related quality of life assessment of children and adolescents. In Drotar D (Ed.), *Measuring Health-Related Quality of Life in Children and Adolescents: Implications for Research and Practice* (pp. 3–24). Mahwah, New Jersey: Lawrence Erlbaum Associates.
- Lewin AB, LaGreca AM, Geffken GR, Williams LB, Duke DC, Storch EA, & Silverstein JH (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. doi: 10.1093/jpepsy/jsp032 [PubMed: 19423660]
- Lohan A, Morawska A, & Mitchell A (2015). A systematic review of parenting interventions for parents of children with type 1 diabetes. *Child: Care, Health and Development*, 41, 803–817. doi: 10.1111/cch.12278
- Lohr KN, & Zebrack BJ (2009). Using patient-reported outcomes in clinical practice: Challenges and opportunities. *Quality of Life Research*, 18, 99–107. doi: 10.1007/s11136-008-9413-7 [PubMed: 19034690]
- Markowitz JT, Volkening LK, Butler DA, Antisdel-Lomaglio J, Anderson BJ, & Laffel LM (2012). Re-examining a measure of diabetes-related burden in parents of young people with type 1 diabetes: The Problem Areas in Diabetes Survey - Parent Revised version (PAID-PR). *Diabetic Medicine*, 29, 526–530. doi: 10.1111/j.1464-5491.2011.03434.x [PubMed: 21883443]
- McBroom LA, & Enriquez M (2009). Review of family-centered interventions to enhance the health outcomes of children with type 1 diabetes. *The Diabetes Educator*, 35, 428–438. doi: 10.1177/0145721709332814 [PubMed: 19299519]
- Patton SR, Dolan LM, Henry R, & Powers SW (2008). Fear of hypoglycemia in parents of young children with type 1 diabetes. *Journal of Clinical Psychology in Medical Settings*, 15, 252–259. doi: 10.1007/s10880-008-9123-x [PubMed: 19104970]
- Polonsky WH, Fisher L, Hessler D, & Johnson N (2016). Emotional distress in the partners of type 1 diabetes adults: Worries about hypoglycemia and other key concerns. *Diabetes Technology & Therapeutics*, 18, 292–297. doi: 10.1089/dia.2015.0451 [PubMed: 26859072]
- Speight J, Holmes-Truscott E, Hendrieckx C, Skovlund S, & Cooke D (2019). Assessing the impact of diabetes on quality of life: What have the past 25 years taught us? *Diabetic Medicine*, 37, 483–492. doi: 10.1111/dme.14196
- Streisand R, Braniecki S, Tercyak KP, & Kazak AE (2001). Childhood illness-related parenting stress: The Pediatric Inventory for Parents. *Journal of Pediatric Psychology*, 26, 155–162. doi: 10.1093/jpepsy/26.3.155 [PubMed: 11259517]

- Streisand R, & Monaghan M (2014). Young children with type 1 diabetes: Challenges, research, and future directions. *Current Diabetes Reports*, 14, 520. doi: 10.1007/s11892-014-0520-2 [PubMed: 25009119]
- Taber KS (2018). The Use of Cronbach's Alpha When Developing and Reporting Research Instruments in Science Education. *Research in Science Education*, 44, 1273–1296. doi: 10.1007/s11165-016-9602-2
- Trief PM, Fisher L, Sandberg J, Cibula DA, Dimmock J, Hessler DM, & Weinstock RS (2016). Health and psychological outcomes of a telephonic couples behavior change intervention in patients with poorly controlled type 2 diabetes: A randomized clinical trial. *Diabetes Care*, 39, 2165–2173. doi: 10.2337/dc16-0035 [PubMed: 27456837]
- Trief PM, Jiang Y, Beck R, et al. (2017). Adults with type 1 diabetes: Partner relationships and outcomes. *Journal of Health Psychology*, 22, 446–456. [PubMed: 26391790]
- Vandagriff JL, Marrero DG, Ingersoll GM, & Fineberg NS (1992). Parents of children with diabetes: What are they worried about? *The Diabetes Educator*, 18, 299–302. doi: 10.1177/014572179201800407 [PubMed: 1628530]
- Varni JW, Delamater AM, Hood KK, Raymond JK, Chang NT, Driscoll KA, ... Wilson DP; 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. doi: 10.2337/dc17-2707 [PubMed: 30061317]
- Ware J Jr., Kosinski M, & Keller SD (1996). A 12-item Short-Form Health Survey: Construction of scales and preliminary tests of reliability and validity. *Medical Care*, 34, 220–233. doi: 10.1097/00005650-199603000-00003 [PubMed: 8628042]
- Wasserman RM, Hilliard ME, Eshtehardi SS, Cao VT, McKinney BM, Marrero DG, & Anderson BJ (2017). Developmental shifts in worries about life with type 1 diabetes (T1D) from childhood through young adulthood. *Diabetes*, 66, 868. [PubMed: 28096257]
- 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. [PubMed: 21443583]
- Weissberg-Benchell J, Shapiro JB, Hood K, Laffel LM, 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. doi: 10.1111/dme.13930 [PubMed: 30761592]
- Whittemore R, Jaser S, Chao A, Jang M, & Grey M (2012). Psychological experience of parents of children with type 1 diabetes: A systematic mixed-studies review. *The Diabetes Educator*, 38, 562–579. doi: 10.1177/0145721712445216 [PubMed: 22581804]
- Wu Y, Thompson D, Aroian KJ, McQuaid EL, & Deatrick JA (2016). Commentary: Writing and evaluating qualitative research reports. *Journal of Pediatric Psychology*, 41, 493–505. doi: 10.1093/jpepsy/jsw032 [PubMed: 27118271]
- 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 JS, Hood K, & Peyrot M (2016). Psychosocial care for people with diabetes: A position statement of the American Diabetes Association. *Diabetes Care*, 39, 2126–2140. doi: 10.2337/dc16-2053 [PubMed: 27879358]

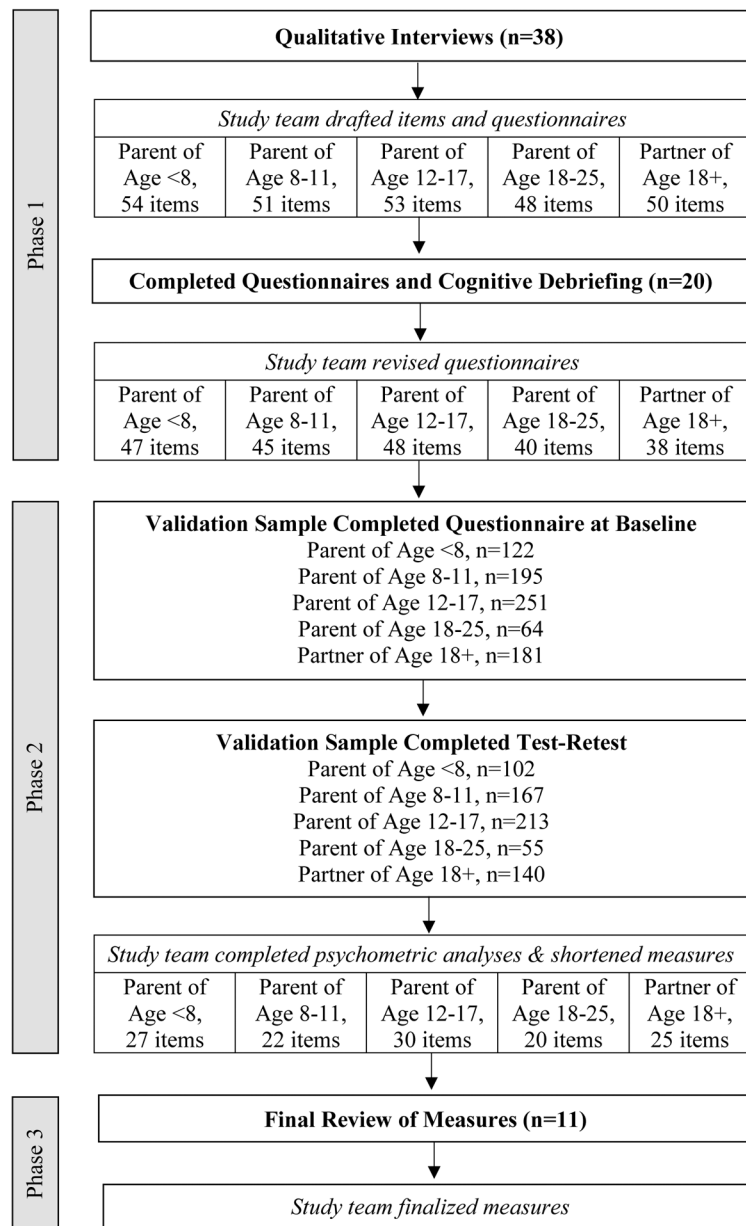


Figure 1. Flow chart of study phases.

Table 1.

Participant characteristics by study phase.

Demographic Characteristics	Phase 1		Phase 2				Phase 3	
	Qualitative	Debriefing	Parent <8	Parent 8-11	Parent 12-17	Parent 18-25	Partner 18	Debriefing
N ^o	38	20	122	195	251	64	181	11
PWD age, M±SD, yrs	22.9±18.0	22.6±18.7	6.1±1.4	10.2±1.1	14.9±1.8	20.5±2.0	47.2±16.8	16.0±9.2
P/P age, M±SD, yrs			35.5±5.5	39.3±8.7	44.1±7.4	49.7±7.3	47.3±17.0	36.5±12.3
PWD gender, % fem.	42%	40%	52%	49%	47%	50%	55%	73%
P/P gender, % fem.	76%	75%	79%	81%	80%	88%	52%	64%
P/P Race/Ethnicity, %								
Hispanic	18%	15%	21%	20%	25%	9%	6%	9%
Non-Hispanic White	61%	55%	69%	68%	64%	88%	90%	91%
Non-Hispanic Black	21%	20%	7%	8%	6%	3%	1%	0%
Other	0%	10%	3%	5%	6%	0%	3%	0%
% living together [‡]	74%	80%	84%	78%	76%	97%	73%	
P/P education, %								
Less than 12 th grade	3%	0%	1%	5%	6%	2%	2%	0%
High school/GED	46%	8%	12%	16%	19%	14%	14%	0%
Some college, no degree	0%	0%	23%	21%	24%	25%	18%	0%
2 year college/tech or associated degree	0%	0%	14%	13%	12%	19%	14%	0%
2/4-yr college degree	35%	45%	33%	30%	26%	27%	26%	55%
Graduate degree	16%	45%	17%	14%	14%	14%	27%	45%
PWD health insurance, % private ^{‡‡}	68%	65%	66%	65%	65%	70%	85%	82%

Notes: N^o indicates n with calculable TIDAL scores (Phase 2 only) [‡] for parents of youth, this refers to parents' marital status – married or partnered and living together; for parents of young adults, this refers to participant (parent) and PWD living together some or most of the time; for partners of adults, refers to participant (partner) and PWD marital status – married or partnered and living together.

^{‡‡} includes private only and private + public insurance. PWD = person with diabetes. P/P = parent/partner.

Table 2.

Preliminary data for original versions of measure used in factor analysis.

Version	n	Items	Internal consistency (α)	α with variable deleted (range across items)
Parent of PWD <8 years old	122	47	0.91	0.90–0.91
Parent of PWD 8–11 years old	195	45	0.88	0.88–0.88
Parent of PWD 12–17 years old	251	48	0.89	0.88–0.89
Parent of PWD 18–25 years old	64	40	0.87	0.86–0.87
Partner of PWD 18 years old	181	36 [^]	0.87	0.86–0.88

[^] Note: The original partner measures included 36 (Partner of Young Adult age 18–25), 38 (Partner of Adult age 26–45), 38 (Partner of Adult age 46–60), and 40 (Partner of Older Adult age >60) items in the validation study. Given the final sample sizes of partners of adults, we collapsed across age-bands for partners and only analyzed the 36 items that were common across all of the partner measures.

Table 3.

Final TIDAL total and subscale scores and reliability estimates.

Version	Scale Name	No. Items	Fleisch-Kincaid	M±SD	Internal Consistency (α^*)	Test-retest (r)
	Total	27	7.7	60.7±15.2	0.88	0.86*
Parent <8	Emotional Experiences & Daily Activities	11		45.3±20.3	0.84	0.80*
	Family Relationships	7		56.4±21.2	0.76	0.77*
	Interactions with Friends and Others	6		87.5±17.3	0.77	0.57*
	Interactions with Healthcare Team	3		75.6±18.6	0.76	0.78*
	Total	22	7.5	64.9±13.6	0.80	0.76*
Parent 8–11	Social and Emotional Experiences	12		52.0±17.9	0.80	0.78*
	Family Relationships	4		91.3±14.9	0.74	0.66*
	Financial Considerations	3		64.9±29.9	0.73	0.76*
	Interactions with Healthcare Team	3		84.3±18.4	0.64	0.40*
	Total	30	7.7	60.0±14.0	0.86	0.83*
Parent 12–17	Emotional Experiences & Daily Activities	14		48.1±19.6	0.86	0.81*
	Sources of Support	8		75.9±15.7	0.72	0.67*
	Handling Diabetes Well	5		64.6±26.4	0.66	0.73*
	Financial Considerations	3		65.5±19.9	0.64	0.65*
	Total	20	7.5	59.1±16.1	0.84	0.73*
Parent 18–25	Emotional Experiences & Daily Activities	11		51.2±18.6	0.80	0.75*
	Parent-Young Adult Relationships	7		71.7±22.0	0.82	0.65*
	Financial Considerations	2		59.0±32.6	0.69	0.60*
	Total	25	7.8	64.6±15.1	0.86	0.77*
Partner 18	Emotional Experiences	9		68.6±19.5	0.80	0.74*
	Diabetes Management & Health Concerns	7		77.9±21.2	0.82	0.79*
	Relationship Impact	6		64.5±26.5	0.61	0.69*

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Version	Scale Name	No. Items	Fleisch-Kincaid	M±SD	Internal Consistency (α)	Test-retest (r)
	Financial Considerations	3		48.3±15.4	0.43	0.69*

Note:

° Standardized Cronbach's alpha

* $p < 0.0001$

Table 4.

Descriptive statistics of validation measures (Phase 2)

<i>Measure</i>	Parent <8	Parent 8–11	Parent 12–17	Parent 18–25	Partner 18
PWD HbA1c, M±SD	7.9±1.1	8.2±1.2	8.7±1.7	8.4±1.4	7.9±1.6
SF-12 – MCS	43.0±10.6	44.3±11.1	45.2±10.6	45.3±10.4	47.7±10.3
SWLS	25.1±7.0	25.8±6.1	25.0±6.9	24.8±6.1	26.4±6.1
PAID-PR	34.3±14.6	39.6±14.3	69.5±27.1		
DDS-P				19.7±16.2	18.1±15.2
DFIS	26.8±8.0	23.9±6.1	22.5±5.8		
SCI-R	69.3±21.8	71.8±17.0			

Notes: PWD = person with diabetes. SWLS = Satisfaction with Life Scale. PAID-PR = Problem Areas in Diabetes – Parent Survey Revised. DDS-P = Diabetes Distress Scale – Partner Version. SF-12 MCS = Short Form Health Survey 12, Version 2, Mental Health Composite Score. SCI-R= Self-Care Inventory-Revised. HbA1c = Hemoglobin A1c.

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Table 5.

Validity estimates for TIDAL total and subscale scores.

Version	Scale	SWLS	PAID	DDS-P	DFIS	SF-12 MCS	SCI-R	HBAIC
Parent <8	Total	0.35**	0.74**		-0.71**	0.50**	0.10	0.10
	Emotional Experiences & Daily Activities	0.26**	0.71**		-0.69**	0.47**	0.11	0.03
	Family Relationships	0.35**	0.59**		-0.50**	0.46**	-0.06	0.13
	Interactions with Friends and Others	0.19*	0.30**		-0.27**	0.17	0.07	0.08
	Interactions with Healthcare Team	0.26**	0.40**		-0.45**	0.26**	0.22*	0.11
Parent 8-11	Total	0.53**	0.71**		-0.64**	0.53**	0.19**	-0.01
	Social and Emotional Experiences	0.53**	0.77**		-0.58**	0.56**	0.14	0.04
	Family Relationships	0.13	0.13		-0.06	0.07	0.06	-0.27**
	Financial Considerations	0.22**	0.33**		-0.57**	0.31**	0.12	-0.01
	Interactions with Healthcare Team	0.24**	0.16*		-0.15*	0.10	0.19**	0.01
Parent 12-17	Total	0.46**	-0.63**		-0.61**	0.49**		-0.12
	Emotional Experiences & Daily Activities	0.35**	-0.63**		-0.58**	0.43**		-0.07
	Sources of Support	0.44**	-0.45**		-0.33**	0.41**		-0.26**
	Handling Diabetes Well	0.11	-0.14*		-0.44**	0.13*		-0.04
	Financial Considerations	0.32**	-0.24**		-0.25**	0.31**		0.02
Parent 18-25	Total	0.46**		-0.76**		0.37**		-0.18
	Emotional Experiences & Daily Activities	0.45**		-0.57**		0.42**		0.06
	Parent-Young Adult Relationships	0.25*		-0.68**		0.09		-0.36**
	Financial Considerations	0.26		-0.26		0.35**		-0.26
	Partner 18	Total	0.53**		-0.78**		0.41**	
Emotional Experiences		0.45**		-0.67**		0.38**		-0.21**
Diabetes Management & Health Concerns		0.38**		-0.69**		0.27**		-0.36**
Relationship Impact		0.34**		-0.22**		0.20**		-0.02
Financial Considerations		0.37**		-0.63**		0.37**		-0.24**

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Notes:

* $p < .05$,

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$p < .01$.

SWLS = Satisfaction with Life Scale, PAID = Problem Areas in Diabetes, DDS-P = Diabetes Distress Scale – Partner Version, SF-12 MCS = Short Form Health Survey 12, Version 2, Mental Health Composite Score, SCIR= Self-Care Inventory-Revised, HbA1c = Hemoglobin A1c.