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Diabetes-specific Health-related Quality of Life in Young Women with Type 1 Diabetes and Body Image Concerns

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Abstract

Background

Young women with type 1 diabetes are at heightened risk for impaired health-related quality of life (HRQoL). Furthermore, this group is vulnerable to disordered eating, which is also linked to reduced quality of life. Although numerous questionnaires assess HRQoL, existing measures are limited conceptually, psychometrically, and logistically. The recently developed Type 1 Diabetes And Life (T1DAL) questionnaire overcomes many of these limitations but has not yet been evaluated in at-risk populations. This study aimed to provide descriptive data on diabetes-specific HRQoL, assessed with the T1DAL, in young women with type 1 diabetes experiencing body image concerns, and to examine demographic, clinical, and disordered eating correlates.

Methodology

: Baseline data (N = 293) from the *Diabetes Body Project* were used. Participants (14–35 years) completed age-appropriate versions of the T1DAL questionnaire alongside other self-report measures assessing disordered eating risk factors and behaviors, an eating disorder diagnostic interview and (diabetes-related) psychological variables. Stepwise regression analyses were performed to identify variables correlated with HRQoL.

Results

Adolescents had a mean T1DAL score of 51.7 ± 12.4, young adults 54.7 ± 13.0, and adults 59.9 ± 13.2. Higher HRQoL was significantly associated with fewer disordered eating behaviors (DEPS-R; ß= -0.53), older age (ß=0.35), and insulin pump use (ß=4.59). A small, non-significant association was observed between lower HRQoL and higher HbA1c levels (ß= -1.19). Together, these variables explained 36% of the variance in HRQoL. Participants scoring above the clinical cut-off for disordered eating (DEPS-R ≥ 20) scored on average 12 points lower on the T1DAL.

Conclusions

Young women with type 1 diabetes and body image concerns appear at risk for lower diabetes-specific HRQoL, especially those who report more diabetes-specific disordered eating behaviors, are younger, do not use an insulin pump, and have higher HbA1c. Notably, only diabetes-specific disordered eating behaviors - rather than generic eating behaviors or body image concerns - were associated with HRQoL, suggesting that the interplay between diabetes and disordered eating is particularly relevant. The T1DAL provided a broad assessment of diabetes-specific HRQoL and may be a valuable tool for monitoring HRQoL in clinical practice.

Background

Type 1 diabetes (T1D) is a chronic autoimmune disease characterized by the destruction of pancreatic beta-cells, resulting in an absolute deficiency of insulin [1]. T1D care requires lifelong, intensive self-management, including daily insulin administration, blood glucose monitoring, and lifestyle adjustments to prevent acute complications and long-term health issues [1]. Given these continuous efforts and that no curative treatment currently exists for T1D, it is crucial to consider the well-being and quality of life (QoL) of individuals living with the condition [2–5].

QoL is a comprehensive, multidimensional construct, defined by the World Health Organization as “an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” [6]. Across populations and scientific disciplines, QoL carries different meanings, which makes it challenging to evaluate it consistently. One way to operationalize it is by focusing on Health-Related Quality of Life (HRQoL), which refers to a person’s physical, mental, and social well-being in relation to their health and it encompasses satisfaction with daily living, functional ability, emotional well-being, social engagement, satisfaction with health and medical care, and health related concerns [7]. HRQoL is one of the more widely used Person-Reported Outcomes (PROs), and efforts have been made to identify correlates of HRQoL in individuals with T1D [5].

First, several demographic variables have been implicated. Previous studies indicate that adolescents and young adults with T1D frequently report lower HRQoL [8 9]. Adolescence and young adulthood represent critical developmental stages characterized by hormonal changes, psychological immaturity, a pursuit of autonomous control, and limited disease acceptance—all of which can negatively impact HRQoL [10 11]. Sex also appears to be a relevant factor, with women consistently reporting lower HRQoL scores than men [9 10 12 13]. Second, several clinical variables have been shown to be associated with HRQoL, including diabetes technology use and metabolic indicators such as glycated hemoglobin (HbA1c) and Time In Range (TIR) [9 14 15].

Another factor influencing HRQoL, though less extensively studied, is the presence of disordered eating behaviors and eating disorders (EDs) [4]. Specifically, young women with T1D are a high-risk group for developing either sub-threshold disordered eating behaviors (i.e., behaviors that do not meet the full diagnostic criteria as outlined in manuals such as the DSM-5) or EDs [16]. The reported prevalence of disordered eating in people with T1D ranges from 8% to 55%, depending on the used definitions and assessment methods [17–20]. Prospective research has indicated that factors such as pressure to be thin, internalization of the thin ideal, body dissatisfaction, negative affect, and female sex predict the onset of ED, and that prodromal ED symptoms, particularly compensatory weight-control behaviors such as fasting, excessive exercise, and insulin omission increase the risk for future emergence of ED [21–25]. Previous research has also demonstrated that eating problems can lead to impaired well-being and reduced QoL among individuals with T1D [4 26], highlighting the need for particular attention to young women with T1D who are at risk for ED. However, it remains unclear which specific behaviors and/or risk factors are most strongly correlated with HRQoL.

Identifying correlates of lower HRQoL is important, as this knowledge can inform health care professionals which individuals may require additional support and which domains warrant particular attention. This is especially relevant given that psychological well-being often receives limited consideration in routine diabetes care, where consultations are brief and predominantly focused on glycemic parameters. Moreover, although recognized by the American Diabetes Association (ADA) and others to be well positioned to address psychosocial concerns, health care professionals report limited confidence or training in addressing mental health concerns [27 28]. Gaining a better understanding of HRQoL and its associated factors in a defined at-risk group may help guide healthcare professionals in clinical practice.

Adequate assessment of HRQoL is a prerequisite for both research and clinical practice. HRQoL can be assessed using either generic or disease-specific measures. Whereas generic measures allow comparisons across populations and health conditions, disease-specific measures capture factors most relevant to those living with the condition [29]. Accordingly, the present study focused on diabetes-specific HRQoL. Although several questionnaires have been developed to assess diabetes-specific HRQoL, research has identified recurring

conceptual, psychometric, and logistical limitations [5 29 30]. Conceptually, the term HRQoL is often applied to measures that in fact assess related constructs, such as diabetes distress, self-management, or treatment satisfaction, thereby confounding HRQoL with other PROs. Psychometrically, reliability and validity data are frequently absent or weak, and many measures blend type 1 and type 2 diabetes or lack a developmental perspective, limiting their ability to capture HRQoL across different life stages. Logistically, existing measures may impose a considerable response burden and often lack options to indicate that certain items are not applicable to the respondent. The recently developed Type 1 Diabetes And Life (T1DAL) questionnaire was designed to overcome these limitations: it was developed with and for people with T1D, comprises developmentally tailored versions across the lifespan—including versions for adolescents and (young) adults—and has demonstrated adequate validity, reliability, and empirically derived subscales [31 32]. However, as a novel instrument, the T1DAL has not yet been evaluated in specific at-risk populations, such as young women with T1D experiencing body image concerns, and descriptive data to support the interpretation of its scores are limited.

To address these gaps, the present study first aimed to provide descriptive data on diabetes-specific HRQoL, assessed with the recently developed T1DAL questionnaire, in a high-risk group: young women with T1D experiencing body image concerns. Second, we examined which demographic and clinical characteristics are associated with diabetes-specific HRQoL in this group, as this may help identify individuals at risk for lowered HRQoL. Third, we explored how disordered eating characteristics relate to diabetes-specific HRQoL.

Methods

Study design and population

For this study, baseline data from an ED-prevention intervention study (the *Diabetes Body Project)* was used. Data was collected across 4 sites and 3 countries: Amsterdam UMC (Netherlands), Oslo University Hospital (Norway), Joslin Diabetes Center (US) and Stanford University (US). Participants had to be between 14–35 years old, female with T1D > 1 year, and experience some level of body image concerns. Females were excluded if they were hospitalized for ED treatment or had ED-related diabetes ketoacidosis in the past year. For more information on recruitment, see the protocol article [33]. The trial has been preregistered (NCT05399446). Ethical approval was obtained at each site [33].

Measures

Questionnaire and interview data were collected at baseline. Demographic variables (age, BMI, ethnicity, education, and employment) were self-reported at baseline. The psychometric properties of the measurement instruments have been reported in the protocol article [33].

Diabetes-specific HRQoL

The *Type 1 Diabetes and Life* (T1DAL) measure was used to assess diabetes-specific HRQoL on a scale ranging from 1 (serious problem) to 5 (no problem), with higher scores indicating better HRQoL. Three age-appropriate versions of the T1DAL were employed: the Adolescent version (12–17 years, 23 items), the Young Adult version (18–25 years, 27 items), and Adult version (26–45 years, 27 items). The questionnaires are tailored to reflect concerns specific to different developmental stages, with wording adapted to the respective age groups[31 32].

Both a total score and subscale scores can be calculated. All three T1DAL questionnaires include the subscales "(Daily) Emotional Experiences & Daily Activities" and "Peer Relationships". The Adolescent and Young Adult versions additionally contain the subscale "Handling Diabetes Well". The Adolescent and Adult versions include the subscale "Family Relationships", while the Young Adult and Adult versions include the subscale "Healthcare Experiences". The Adult version also features an additional subscale titled "Financial Considerations. Scores are computed by subtracting one from the raw item scores, summing the adjusted values, dividing by the number of items, and multiplying this result by 25. This transforms the scores to a 0-100 scale, which enables comparison across the different versions of the questionnaire. The number of items is defined as the number of items answered, excluding those for which the response "does not apply" was selected. For the Young Adult and Adult version, several extra "does not apply" response options were included for only the European participants, as these refer to items concerning financial considerations (T1DAL Young Adult: items 23 and 24; T1DAL Adult: items 22, 23, and 24). This adaptation was made in consideration of structural differences between healthcare and insurance systems in the U.S. and EU.

Disordered eating variables

• Eating disorder symptoms

- The semi-structured *Eating Disorder Diagnostic Interview* (EDDI) assesses DSM-5 ED symptoms. Interviews were conducted by independent interviewers via telephone. A continuous symptom composite was calculated to reflect the presence of symptoms over the past 30 days [23].

• Diabetes-specific disordered eating behaviors

- The *Diabetes Eating Problem Survey–Revised* (DEPS-R; 16 items) was used to assess diabetes-specific disordered eating behaviors. Items were rated on a scale from 0 (never) to 5 (always), with higher scores indicating greater levels of disordered eating [34]. A score of ≥ 20 indicates elevated levels of disordered eating behaviors [34].

• Pursuit of the thin appearance ideal

- The *Thin-Ideal Internalization Scale* (TIIS; 8 items) was used to measure pursuit of the thin appearance ideal. Responses were rated on a scale from 1 (strongly disagree) to 5 (strongly agree), with higher scores indicating greater internalization of the thin appearance ideal [23 35].

• Body dissatisfaction

- The *Satisfaction and Dissatisfaction with Body Parts Scale* (9 items) was used to measure satisfaction with different body parts on a scale from 1 (extremely dissatisfied) to 5 (extremely satisfied). Responses were reverse-coded, such that higher scores reflected higher levels of body dissatisfaction [36].

• Dietary restraint

- The *Restrained eating Subscale* of the *Dutch Eating Behavior Questionnaire* (DEBQ-RS; 10 items) was used to assess dietary restraint. Items were rated on a scale from 1 (never) to 5 (always), with higher scores indicating greater restriction of food intake for the purpose of promoting weight loss or preventing weight gain [37].

Clinical variables

Diabetes duration and technology use (insulin pump and/or continuous glucose monitor (CGM) were self-reported.

• HbA1c

Objectively assessed HbA1c, which measures average blood glucose levels over the last 2 to 3 months, was measured through the use of self-test kits or at the respective diabetes clinics. The general recommended target HbA1C for people with T1D is 53 mmol/mol (7.0%) or lower.

• Blood glucose time-in-range (TIR)

Participants who used a CGM sent a photo/screen shot of the percentage of time spent within, above, and below target range (70–180 mg/DL, 3,9–10,0 mmol/mol) of the 14 days prior. The recommended TIR is 70% or above.

Statistical analysis

Spearman correlation analyses were used to assess correlations between the continuous variables, see supplementary materials. To assess the linearity assumption between the continuous covariates and outcome variable, we employed restricted cubic splines [38]. Spline terms were fitted, using the splines package in R, and tested for significance. For most continuous covariates, the restricted cubic spline function did not improve the fit of the model. For the covariate 'thin appearance ideal', the cubic spline function did significantly improve the model fit, as indicated by an increase in R-squared from 0.31 to 0.32 compared to a linear model ($p < 0.05$). Assumptions of homoscedasticity and normality of residuals were verified and met across all regression models. All categorical variables were recoded into fewer categories or dichotomized for analytical purposes. Ethnicity was dichotomized into White and Non-White. Education was classified into three categories: some education (grade school, some high school), secondary education (high school, some college but no degree, trade school, associate's degree), and higher education (bachelor's degree, master's degree, PhD or higher). Employment status was categorized as student, working, or other. A stepwise multiple regression analysis was conducted to identify variables associated with diabetes-specific HRQoL among young women with T1D. Independent variables were entered in three sequential models: (1) demographic variables (age, BMI, ethnicity, education level, and employment status); (2) clinical variables (diabetes duration, pump use, HbA1c % and TIR); and (3) disordered eating-related variables (general ED symptoms, diabetes-specific disordered eating behaviors, pursuit of the thin appearance ideal, body dissatisfaction, and dietary restraint). In the fourth model, the remaining variables from the first three models were added to a backward linear regression analysis. All models were corrected for study site. The selection of variables was determined based on the Akaike Information Criterion. Post hoc analyses (scatterplots and independent t-tests) were conducted to further explore the relationship between disordered eating variables that were significant in the regression model and HRQoL. All statistical analyses were performed using RStudio, version 2024.12.1.

Results

A total of 293 participants completed the baseline assessment (Table 1). Mean age was 25 years (SD = 5.5), with a mean BMI of 26.5 kg/m^2 (SD = 5.6). The majority were white (90.1%) and highly educated (56.7% having a bachelor's degree or higher). Nearly all participants used diabetes technology, with 79.5% using an insulin pump

and 98.3% using CGM. Mean HbA1c was 7.01% (SD = 0.96) and mean TIR was 65.9% (SD = 16.9). The population had a mean DEPS-R score of 19.4 (SD = 11.3), just below the threshold of 20 (indicative of disordered eating behaviors), with 131 participants (44.7%) scoring above the threshold.

Table 1
Participant characteristics at pretest (baseline)

	Total N = 293
Demographic variables	
Age (years)	25.02 (5.5)
BMI (kg/m^2)	26.5 (5.6)
Ethnicity, n (%)	12 (4.1)
• Asian	5 (1.7)
• Black	1 (0.3)
• Native Hawaiian or other Pacific Islander	264 (90.1)
• White	5 (1.7)
• Other	6 (2.0)
• Did not disclose	
Hispanic, n (%)	25 (8.5)
Education, n (%)	11 (3.8)
• Grade school	23 (7.8)
• Some high school	21 (7.2)
• High school degree or equivalent (e.g. GED)	54 (18.4)
• Some college but no degree	10 (3.4)
• Trade school	8 (2.7)
• Associate's degree	109 (37.2)
• Bachelor's degree	50 (17.1)
• Master's degree	7 (2.4)
• PhD or higher	
Employment, n (%)	103 (79.2)
• Student	39 (13.3)
• Employed part-time	121 (41.3)
• Employed full-time	10 (3.4)
• Seeking opportunities	20 (6.8)
• Other	
Clinical variables	

BMI: Body Mass Index, HbA1c: glycated hemoglobin, EDDI: Eating Disorder Diagnostic Interview, DEPS-R: Diabetes Eating Problem Survey-Revised, DEBQ-RS: Dutch Eating Behavior Questionnaire – Restrained Scale, TIIS: Thin Ideal Internalization Scale, BD: The Satisfaction and Dissatisfaction with Body Parts Scale

	Total N = 293
Demographic variables	
Diabetes duration (years)	11.5 (6.2)
Pump use, n (%)	233 (79.5)
Sensor use, n (%)	283 (98.3)
HbA1c	7.01 (1.0)
• % (SD)	53.2 (10.5)
• mmol/mol (SD)	
Blood glucose time in range (%)	65.9 (16.9)
Disordered eating variables	
Eating disorder symptoms (EDDI)	12.8 (12.2)
Diabetes-specific disordered eating behaviors (DEPS-R)	19.4 (11.3)
Dietary restraint (DEBQ-RS)	2.7 (0.8)
Pursuit of the thin appearance ideal (TIIS)	3.4 (0.7)
Body dissatisfaction (BD)	3.4 (0.7)

BMI: Body Mass Index, HbA1c: glycated hemoglobin, EDDI: Eating Disorder Diagnostic Interview, DEPS-R: Diabetes Eating Problem Survey-Revised, DEBQ-RS: Dutch Eating Behavior Questionnaire – Restrained Scale, TIIS: Thin Ideal Internalization Scale, BD: The Satisfaction and Dissatisfaction with Body Parts Scale

Table 1
Correlations for Outcomes at Pretest (baseline)

Outcome	EDDI	DEPS-R	DEBQ-RS	TIIS	BD	T1DAL	TIR	HBA1C	BMI	DIABETES DURATION
Eating disorder symptoms (EDDI)	1									
Diabetes-specific disordered eating behaviors (DEPS-R)	.63	1								
Dietary Restraint (DEBQ-RS)	.44	.48	1							
Pursuit of the thin ideal (TIIS)	.17	.28	.22	1						
Body dissatisfaction (BD)	.42	.48	.36	.25	1					
Diabetes-related quality of life (T1DAL)	− .32	− .51	− .17	− .11	− .29	1				
Blood glucose time-in-range (TIR)	− .16	− .26	.04	.03	− .08	.26	1			
HbA1c (%)	.15	.29	.01	− .08	.03	− .26	− .71	1		
BMI	.26	.23	.10	.06	.31	− .06	− .19	.06	1	
Diabetes duration	.06	− .02	.07	− .01	− .01	.04	.12	− .14	− .07	1

Note:, EDDI: Eating Disorder Diagnostic Interview, DEPS-R: Diabetes Eating Problem Survey-Revised, DEBQ-RS: Dutch Eating Behavior Questionnaire – Restrained Scale, TIIS: Thin Ideal Internalization Scale, BD: The Satisfaction and Dissatisfaction with Body Parts Scale, T1DAL: Type 1 Diabetes And Life, TIR: Time-In-Range.

A total of 98.6% of participants (n = 289) completed the T1DAL, including 26 participants aged 14–17 (adolescent cohort), 130 aged 18–25 (young adult cohort), and 133 aged 26–35 (adult cohort). Table 2 presents the mean scores and ranges for the total and subscale scores across the three age-appropriate versions of the T1DAL. The lowest scores were observed on the subscale "(Daily) Emotional Experiences & Daily Activities" across all participants. Participants in both the adolescent and adult cohorts scored highest on the "Family Relationships" subscale, with adolescent participants reporting a mean score of 68.9 (SD = 20.5), and adult participants reporting a mean score of 81.0 (SD = 21.1). In contrast, young adults scored highest on the "Healthcare Experiences" subscale, with a mean score of 71.2 (SD = 17.7). Adult participants also rated the "Healthcare Experiences" subscale highly, but reported significantly lower scores on the "Financial Considerations" subscale (M = 54.7, SD = 28.2), which was not assessed in the adolescent or young adult cohorts.

Table 2
T1DAL mean total and subscale scores

T1DAL adolescent (age 12–17), n = 26	**Mean (SD)**	**Range**
Total score	51.7 (12.4)	27.2–90.2
Mean subscale scores	34.1 (15.2)	11.4–86.4
• Daily Emotional Experiences & Daily Activities	67.9 (17.0)	20.8–100.0
• Handling Diabetes Well	66.3 (20.1)	8.3–100.0
• Peer Relationships	68.9 (20.5)	25.0-100.0
• Family Relationships		
T1DAL young adult (age 18–25), n = 130		
Total score	54.8 (12.9)	21.9–81.5
Mean subscale scores	39.6 (15.9)	4.6–81.3
• Emotional Experiences & Daily Activities	63.1 (18.4)	18.8–100.0
• Handling Diabetes Well	70.3 (19.3)	18.8–100.0
• Peer Relationships	72.7 (17.7)	8.3–100.0
• Healthcare Experiences		
T1DAL adult (age 26–45), n = 133		
Total score	59.9 (13.2)	23.1–92.6
Mean subscale scores	47.2 (15.7)	13.6–90.9
• Emotional Experiences & Daily Activities	81.0 (21.1)	0.0-100.0
• Family Relationships	71.6 (18.7)	25.0-100.0
• Peer Relationships	75.7 (23.5)	0.0-100.0
• Healthcare Experiences	54.7 (28.2)	0.0-100.0
• Financial Considerations		

Results of the stepwise backwards linear regression are presented in Table 3. The first model, in which just age was retained after the backwards regression, significantly explained 10% of the variance in diabetes-specific HRQoL ($p < 0.001$). Participants with a higher age reported significantly higher diabetes-specific HRQoL. In the second model with diabetes specific variables, HbA1c and pump use were retained, explaining 14% of the variance in diabetes-specific HRQoL ($p < 0.001$). Wherein usage of an insulin pump and lower HbA1c levels were associated with higher diabetes-specific HRQoL. In the third model, including disordered eating variables, only diabetes-specific disordered eating behaviors stayed in the model, explaining 32% of the variance in diabetes-specific HRQoL ($p < 0.001$). Participants reporting more diabetes-specific disordered eating behaviors scored significantly lower on diabetes-specific HRQoL. The fourth and final model, consisting of age, HbA1c, pump use, and diabetes-specific disordered eating behaviors, significantly explained 36% of the variance in in diabetes-specific HRQoL ($p < 0.001$).

Table 3
Stepwise backward linear regression analysis examining the association between diabetes-specific health-related quality of life and demographic, clinical, and disordered eating variables (n = 220)

T1DAL Total Score	**Model 1**	**Model 2**	**Model 3**	**Model 4**	**CI95%**
	ß	**ß**	**ß**	**ß**	
1. Demographic variables					
Age (years)	0.49**				0.18;0.81
BMI	-				-
Ethnicity	-				-
Education level	-				-
Employment status	-				-
2. Clinical variables					
TIR (%)		-			-
HbA1c (%)		-3.40*			-5.24;-1.56
Pump use		4.40***			0.14;8.65
Diabetes duration		-			-
3. Disordered eating variables					
Diabetes-specific disordered eating behaviors			-0.58***		-0.71;-0.46
General eating disorder symptoms			-		-
Pursuit of thin appearance ideal			-		-
Body dissatisfaction			-		-
Dietary restraint			-		-
4. Final model					
Age (years)				0.35*	0.08;0.62
HbA1c (%)				-1.19	-2.85;0.47
Pump use				4.59*	0.93;8.26
Diabetes-specific disordered eating behaviors				-0.53***	-0.66;-0.40
Adjusted R^2	0.10***	0.14***	0.32***	0.36***	
ß = standardized regression coefficients					
* p < 0.05; ** p < 0.01; *** P < 0.001					
Analyses were corrected for study site.					
Supplementary materials					

T1DAL Total Score	Model 1	Model 2	Model 3	Model 4	CI95%
	ß	ß	ß	ß	
1. Demographic variables					
Akaike Information Criterion	1108.45	1099.33	1046.15	1035.36	
ß = standardized regression coefficients					
* p < 0.05; ** p < 0.01; *** P < 0.001					
Analyses were corrected for study site.					
Supplementary materials					

As shown in Table 2, of all the disordered eating variables, only diabetes-specific disordered eating behaviors significantly contributed to diabetes-specific HRQoL. To gain a better understanding of this relationship, post-hoc analyses were performed, including a scatterplot (Fig. 1) and an independent samples t-test. Individuals with a DEPS-R score of 20 or higher were compared to those scoring below this cut-off. Both the scatterplot and the t-test demonstrate that individuals with a DEPS-R score above the cut-off report significantly lower diabetes-specific HRQoL (mean difference on T1DAL = -12; p < 0.001; CI95% = -14.64; -9.07).

Discussion

In this study, we evaluated diabetes-specific HRQoL of young women with T1D and body image concerns - a group known to be at increased risk for reduced HRQoL - using the novel T1DAL questionnaire. Furthermore, we aimed to assess which variables were associated with lower diabetes-specific HRQoL, specifically focusing on disordered eating variables. Our findings indicate that diabetes-specific eating problems contribute significantly to lower HRQoL. Together with age, insulin pump use, and HbA1c, these factors explained 36% of the variance in HRQoL.

Upon examining the total and subscale scores of the T1DAL, all age groups reported (slightly) lower diabetes-specific HRQoL compared to previous research [31 32 39 40]. These differences were primarily explained by lower scores on the subscale 'Emotional Experiences & Daily Activities'. This subscale measures the emotional and psychological burden associated with managing diabetes, specifically addressing the impact of diabetes on emotions, daily activities, body image, and eating behaviors. Items related to body image and eating behavior (“I am not satisfied with the shape or size of my body because of my diabetes”, “Dealing with diabetes when I eat is stressful”) may carry additional weight for our study population—young women with T1D and body image concerns—which may partially explain the lower scores on this subscale, and overall lower total scores. This discrepancy may additionally be explained by the exclusion of male participants from this study, as women generally report lower QoL scores compared to men [12 13].

The association with age, where lower age corresponds to poorer HRQoL, aligns with previous studies [10 11]. Diabetes duration was not associated with HRQoL. This suggests that age or developmental stage, rather than the cumulative burden of living with diabetes, plays a more prominent role in shaping HRQoL. As noted, adolescence is a particularly challenging developmental period marked by numerous biological, psychological, and social changes, all of which may negatively affect HRQoL [10]. In addition to age, HbA1c was retained in the final model, although its effect was non-significant, with higher HbA1c levels being associated with lower QoL. This finding is consistent

with prior research [14 15]. It is important to note, however, that the glycemic outcomes in this population were already relatively optimal at baseline, with a mean HbA1c of 7.01% (SD: 0.96). In examining diabetes technology, we opted to focus exclusively on the use of insulin pumps, as nearly all participants (98%) reported to use a CGM. Insulin pump use was positively correlated with HRQoL, with individuals using an insulin pump scoring, on average, 4.6 points higher on the T1DAL compared to those not using an insulin pump. However, given that nearly all participants also reported using a CGM, the observed effect should not be considered solely due to insulin pump use, but also partly reflecting the influence of hybrid closed-loop systems. The impact of automated insulin delivery systems and hybrid closed-loop systems remains underexplored; however, existing research suggests that their effects on psychological well-being are broad, complex, and variable, involving both benefits and potential drawbacks [41–43].

Novel in this study is the examination of (both diabetes-specific and general) ED symptoms in relation to HRQoL. Interestingly, a significant moderate association was found between diabetes-specific disordered eating behaviors, measured using the DEPS-R, and diabetes-specific HRQoL, with more disordered eating behaviors correlating with lower QoL. This finding was further illustrated by the observation that individuals with a DEPS-R score of 20 or higher had significantly lower QoL scores (mean difference of 12 points on the T1DAL) compared to those with a DEPS-R score below 20. Notably, of all the disordered eating behavior variables, only diabetes-specific disordered eating behaviors remained in the final predictive model. This may suggest that the specific link between diabetes and disordered eating behaviors is the primary factor influencing diabetes-specific HRQoL, rather than body image concerns or more generic eating behaviors that individuals may also experience.

Overall, the final model accounted for 36% of the variance. This can be considered an acceptable model for predicting HRQoL: a complex human phenomenon influenced by numerous variables and characterized by high natural variability[44]. While this model does not capture all variables that may be associated with diabetes-specific HRQoL, it highlights the role of age, glycemic parameters, diabetes technology, and disordered eating behaviors. Clinicians should be mindful of these variables in clinical meetings with young people with T1D, especially young women.

Regarding both the scientific and clinical value of the T1DAL, we believe that this questionnaire could make a meaningful contribution. Previous research, as well as guidelines and recommendations from professional associations such as the American Diabetes Association (ADA) and the International Society for Pediatric and Adolescent Diabetes (ISPAD), highlight the importance of routine assessment of well-being and functioning across both pediatric and adult care settings [45–47]. Through the use of PROs, it is possible to look beyond medical (glycemic) outcomes to assess functioning and well-being, with the individual's perspective being central to the assessment [45]. Specifically, in the context of monitoring, where changes over time are tracked, the T1DAL could potentially serve as a valuable Person-Reported Outcome Measure (PROM). The T1DAL provides a comprehensive view of diabetes-specific HRQOL, addressing both potential challenges and positive aspects individuals may experience regarding living with diabetes [31]. Although the instrument has thus far seen limited use in empirical research, it has undergone rigorous psychometric evaluation and serves as the foundation for an intervention aimed at promoting HRQoL [48]. Our research has shown that the T1DAL allows for a wide variety of scores, as evidenced by its subscale scores, which range from low (approximately 0 to 20) to high (approximately 80 to 100). In clinical practice, the T1DAL could be utilized to monitor and assess diabetes-specific HRQOL, including the identification of potential disordered eating behaviors. If necessary, the DEPS-R could then be employed for further and more specific screening of these disordered eating symptoms [49]. Overall, this broader assessment of HRQoL

seems promising for and the T1DAL could serve as a valuable tool for addressing various topics relevant to this vulnerable population of individuals with T1D.

We need to acknowledge the limitations of this study. First, we relied on data from a single timepoint. For this study, we deliberately focused our analyses on only the baseline measurement from the larger ongoing study on the effectiveness of the *Diabetes Body Project* intervention. This decision was made to ensure that our sample reflected young women with T1D prior to any intervention, thereby providing a more ecologically valid and accurate representation of this population as encountered in routine clinical practice. By analyzing pre-intervention data, we aimed to generate some normative values for diabetes-specific HRQoL and its correlates within this specific population. Although this cross-sectional approach limits our ability to infer causality or identify predictors, it establishes an essential foundation for future longitudinal analyses. Second, while we focused on how these variables may impact HRQoL, the true causal relationships between these variables and HRQoL are complex and often reciprocal and cannot be determined based on this data. For instance, HRQoL may also influence glycemic outcomes and disordered eating behaviors, and these variables may also interact with each other [13 50 51]. However, the stepwise approach in the backward regression analyses allowed us to examine a wide range of variables. By grouping similar variables and testing them incrementally, we were able to identify which variables had the greatest impact within each category before combining them in the final model. Third, the study included only young women with body image concerns, which limits the generalizability of the findings. On the other hand, the large sample size, multinational design, and broader age range helped to improve the diversity. Most QoL research has focused either on adolescents or adults; but, with an age range of 14 to 35 years, we were able to include all young adults and examine diabetes-specific HRQoL across several developmental stages. The T1DAL enabled us to assess and compare HRQoL across all these age ranges. This study is among the first to employ the T1DAL questionnaire, which limited opportunities for direct comparison with existing literature and complicated the interpretation of observed scores. Further research is warranted to establish reference values for the T1DAL.

Conclusions

To conclude, HRQoL is a multidimensional construct shaped by a wide array of psychosocial and clinical factors. The present study emphasizes the correlation of age, HbA1c, insulin pump use, and diabetes-specific disordered eating behaviors in young women with T1D and body image concerns with diabetes-specific HRQoL. Furthermore, this study demonstrates the utility of the T1DAL questionnaire for assessing diabetes-specific HRQoL across a broad age range, including adolescents and (young) adults. The instrument allows for substantial variability in scores and provides a comprehensive evaluation of HRQoL domains, including concerns related to disordered eating and body image. These findings provide evidence for the clinical applicability of the T1DAL questionnaire, enabling diabetes health care professionals to systematically monitor and help improve HRQoL.

Abbreviations

ADA
American Diabetes Association
BMI
Body Mass Index
CGM
Continuous Glucose Monitoring
DEBQ-RS

Dutch Eating Behavior Questionnaire-Restrained eating Subscale
DEPS-R
Diabetes Eating Problem Survey-Revised
DSM-5
Diagnostic and Statistical Manual of Mental Disorders–5
ED
eating disorder
EDDI
Eating Disorder Diagnostic Interview
HbA1c
Glycated Hemoglobin
HRQoL
Health-Related Quality of Life
ISPAD
International Society for Pediatric and Adolescent Diabetes
PRO
Person Reported Outcome
PROM
Person Reported Outcome Measure
QoL
Quality of Life
T1D
Type 1 Diabetes
T1DAL
Type 1 Diabetes And Life
TIIS
Thin-Ideal Internalization Scale
TIR
Time In Range

Declarations

Author Contribution

MHCL, LW, and MdW contributed to the study design. All authors were involved in data collection. The formal analysis and writing of the original draft were performed by MHCL, with supervision from LW and MdW. All the authors reviewed and edited the manuscript.

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Data Availability

The authors declare that they have no competing interests.

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Figures

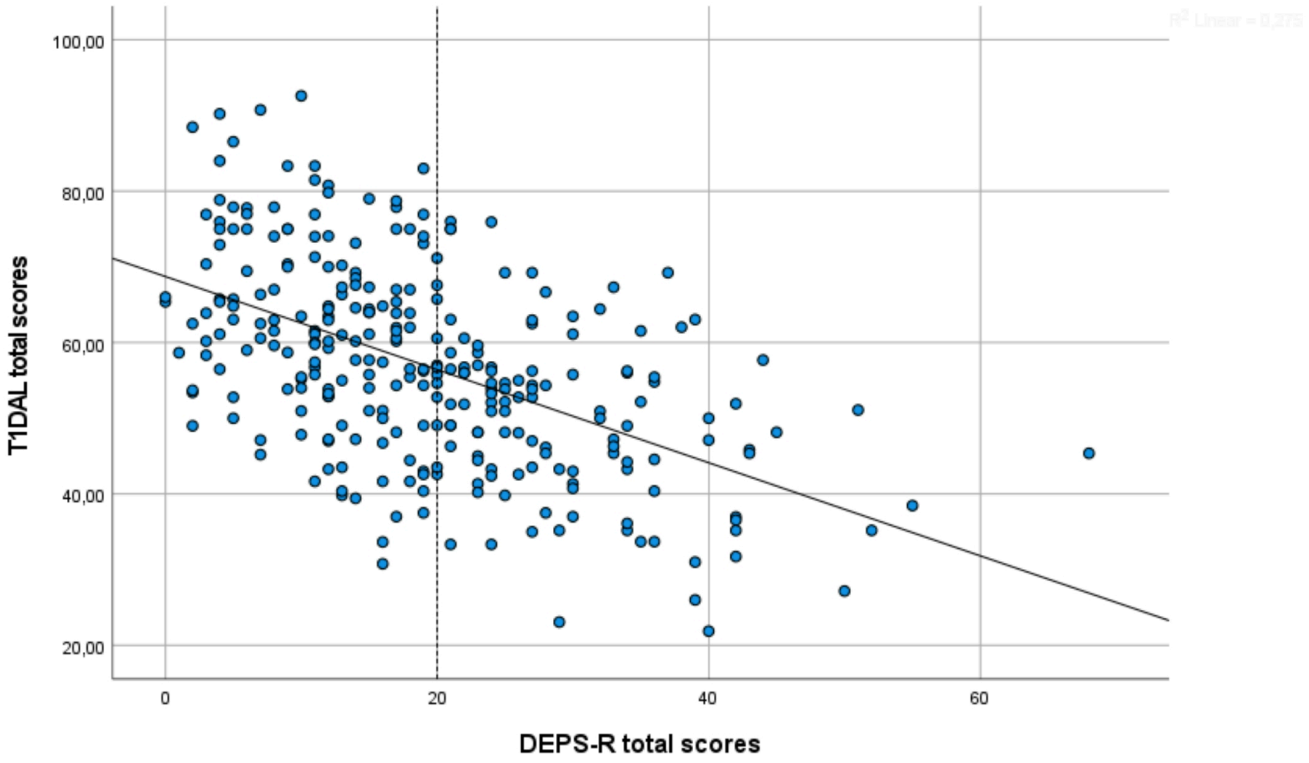


Figure 1

Scatterplot of T1DAL total scores and DEPS-R total scores, with cut-off of 20 on DEPS-R indicating the presence of disordered eating behaviors