Factors Associated With Diabetes-Specific Health-Related Quality of Life in Youth With Type 1 Diabetes: The Global TEENs Study

Diabetes Care 2017;40:1002–1009 | https://doi.org/10.2337/dc16-1990

OBJECTIVE

Our objective was to characterize diabetes-specific health-related quality of life (D-HRQOL) in a global sample of youth and young adults with type 1 diabetes (T1D) and to identify the main factors associated with quality of life.

RESEARCH DESIGN AND METHODS

The TEENs study was an international, cross-sectional study of youth, 8–25 years of age, with T1D. Participants (N = 5,887) were seen in clinical sites in 20 countries across 5 continents enrolled for 3 predetermined age groups: 8–12, 13–18, and 19–25 years of age. To assess D-HRQOL, participants completed the PedsQL Diabetes Module 3.0 and were interviewed about family-related factors. Specifics about treatment regimens and self-management behaviors were collected from medical records.

RESULTS

Across all age groups, females reported significantly lower D-HRQOL than did males. The 19–25-year age group reported the lowest D-HRQOL. Multivariate linear regression analyses revealed that D-HRQOL was significantly related to HbA1c; the lower the HbA1c, the better the D-HRQOL. Three diabetes-management behaviors were significantly related to better D-HRQOL: advanced methods used to measure food intake; more frequent daily blood glucose monitoring; and more days per week that youth had ≥30 min of physical activity.

CONCLUSIONS

In all three age groups, the lower the HbA1c, the better the D-HRQOL, underscoring the strong association between better D-HRQOL and optimal glycemic control in a global sample of youth and young adults. Three diabetes-management behaviors were also related to optimal glycemic control, which represent potentially modifiable factors for clinical interventions to improve D-HRQOL as well as glycemic control.

Contemporary clinical trials of new medications and treatment technologies increasingly include patient-reported outcomes such as quality of life in addition to objective health outcomes (1). Subjective factors such as disease self-management burden or disease impact on social functioning are especially important for individuals with type 1 diabetes (T1D) because T1D is primarily a self-managed condition (2). The Pediatric Self-Management Framework (3) served as the theoretical model for this research on diabetes-specific health-related quality of life (D-HRQOL). The Pediatric

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Self-Management Framework is a comprehensive conceptual model of pediatric self-management that takes into account individual, family, and health care system influences that affect self-management and also describes the relationships among self-management behavior, adherence, and patient outcomes.

As intensive insulin regimens become the standard of care for youth with T1D, the burdens placed on the routines and relationships of youth and their families also increase (4). Consequently, national and international clinical practice guidelines are increasingly recommending that diabetes care providers use HRQOL instruments to assess and care for patients with diabetes (5,6).

For children and teens with a medical condition, HRQOL can include satisfaction with the current status and treatment of the condition; the impact of the condition on physical, social, and emotional functioning; and how much one worries about or is distressed by the condition (7). Instruments that measure HRQOL can capture the impact of having a chronic health condition in general (Generic HRQOL) or may emphasize the particular impact of a specific condition (e.g., diabetes) on everyday life (D-HRQOL). Higher levels of D-HRQOL (i.e., better life quality in relation to diabetes) predict key diabetes outcomes, including greater adherence to treatment recommendations and optimal glycemic control in youth with T1D (8–10), emphasizing its central role in diabetes management and control.

Although D-HRQOL has also been reported to be associated with adherence in youth with T1D, in these studies, adherence is usually measured as a unitary construct using a single score. D-HRQOL has not been examined in relationship to specific self-management behaviors. The identification of specific self-management behaviors that relate to D-HRQOL may help to fill an important gap in understanding the bidirectional relationship between higher D-HRQOL and better glycemic control. Most importantly, as conceptualized in the Pediatric Self-Management Framework (3), self-management behavior is one of the most proximal and potentially modifiable variables available to pediatric care providers as targets for interventions.

The focus of the present report is on the interrelationship between D-HRQOL and glycemic control as well as on the identification of individual, family, and diabetes self-management factors that are associated with optimal D-HRQOL in the global TEENs study. The primary aim of the TEENs study was to characterize diabetes-specific quality of life and glycemic control of a global sample of patients with T1D in three predetermined age groups (8–12, 13–18, and 19–25 years).

**RESEARCH DESIGN AND METHODS**

The TEENs study was a global, observational, cross-sectional study of youth and young adults, 8–25 years of age, with T1D launched across 5 continents in 20 countries in 2012.

**Recruitment Procedures**

In each country, young persons enrolled in the TEENs study received their care in centers with at least 100 pediatric and/or young adult patients with T1D that were representative of the typical medical care delivered in their respective countries. At each of the study centers, the TEENs study protocol was approved by the appropriate Institutional Review Board or ethics review board. Signed written informed consent was obtained from the participant if applicable and from the parent(s)/guardian(s). Youth were enrolled sequentially or randomly to avoid selection bias, with a recruitment ratio of 25/50/25% for the 3 predetermined age groups (school age 8–12 years; adolescents 13–18 years; and young adults 19–25 years). Half of the intended sample included adolescents because of the focus on investigating diabetes management during this developmental stage, recognized for its physiologic and behavioral challenges affecting glycemic control. The recruitment period extended from 14 August 2012 until 6 September 2013.

**Participants**

Inclusion criteria were youth aged 8–25 years, with T1D diagnosed before 18 years of age and duration of diabetes of ≥1 year at enrollment. Participants had no major change in insulin regimen during the last 3 months (no transition between pump and injection therapy). Of the 5,968 participants who were screened, 5,887 were deemed eligible.

**Measures**

Demographic data, treatment characteristics, and self-management behavior data were collected by medical record review. Parents/guardians completed questionnaires and interviews; youth completed questionnaires and interviews.

**Demographic Data**

At each site, demographic data (race/ethnicity and date of birth) were captured from the youth’s medical record (except in France, where government regulations prohibit the collection of patient’s race/ethnicity information).

**D-HRQOL**

All youth (8–25 years) completed the age-appropriate version of the PedsQL Diabetes Module 3.0 (11), the most widely used D-HRQOL measure in youth with T1D (12). The PedsQL Diabetes Module 3.0 has been translated into and validated in multiple languages. The questionnaire is composed of 28 items that are divided into 5 subscales: 1) diabetes symptoms (e.g., feeling hungry); 2) treatment barriers (e.g., embarrassment); 3) treatment adherence (e.g., hard to take blood glucose tests); 4) worry (e.g., going low); and 5) communication problems (e.g., hard for me to explain my illness to other people). Frequently, data from the PedsQL Diabetes Module 3.0 have been reported in terms of scores on the five subscales. However, recently, Hilliard et al. (13) reported that the α coefficients for the original five subscales are lower than desirable, ranging from 0.61 to 0.75. Moreover, the five subscales do not represent statistically distinct measurement factors. Two studies of youth with T1D, Nansel et al. (14) (N = 437) and Lawrence et al., the SEARCH Study Group (15) (N = 2,602), have recently tested the factor structure of the PedsQL Diabetes Module 3.0 and reported that the original five subscales were not supported by factor analyses nor did a clear factor structure emerge from principal components analysis. Both studies reported that a total PedsQL Diabetes Module score was the most psychometrically appropriate use of this measure as compared with analysis of subscale scores. Therefore, we used the total score on the PedsQL Diabetes Module 3.0 in the TEENs study because of its strong psychometric properties.

On the PedsQL Diabetes Module 3.0, the total score ranges between 0 and 100, and higher scores represent better D-HRQOL (16). Two age-specific versions...
of the PedsQL Diabetes Module 3.0 were used: 8–12 and 13–18 years. If a participant in the 8–12-year-old group had problems reading the questionnaire, an interviewer, not the parent, read the questionnaire to the child to avoid parent influence on the child’s responses. Participants in the 19–25-year-old group completed the 13–18-year-old version of the PedsQL Diabetes Module. All of the items on the Teen version of the Diabetes Module were also relevant to the young adult cohort.

**Treatment Characteristics and Self-Management Behavior**

Specifics about each youth’s regimen type (such as insulin delivery method and use of diabetes treatment technologies) and self-management behaviors (such as frequency of daily blood glucose monitoring, amount of physical activity, and dietary strategy [used to manage blood glucose]) were collected from medical records. Objective measures of self-management behaviors, such as blood glucose meter and pump downloads, were not possible because of the inconsistency in centers’ having the computers and software to collect these more objective measures.

**Family Factors**

To gather information about how parents and youth divided up responsibility for the diabetes tasks of administering insulin and monitoring blood glucose levels, two items were taken from the validated Diabetes Family Responsibility Questionnaire (17) and collected by participant interview. Participants were also interviewed about diabetes-specific family conflict based on two questions taken from the validated Revised Diabetes Family Conflict Scale (18). Because of the need to reduce response burden on participants, only two items were selected from each instrument. These items were selected because they focused on the two primary areas of diabetes management: insulin administration and blood glucose monitoring. In other words, diabetes family responsibility-sharing and diabetes family conflict were assessed with respect to insulin administration as well as to blood glucose monitoring. These interview questions based on items from the Diabetes Family Responsibility Questionnaire and Revised Diabetes Family Conflict Scale were translated using standard forward and backward translation methods.

**Glycemic Control**

HbA1c values were not measured in a central laboratory. However, all centers followed standardized procedures, including HbA1c measurement. At all TEENs study sites, glycemic control was measured uniformly using point of care A1cNow (Bayer) (reference range 4–6%) calibrated to Diabetes Control and Complications Trial (DCCT)/NGSP percentage numbers. HbA1c target definitions were based on International Society for Pediatric and Adolescent Diabetes standards for ages 8–12 and 13–18 years as <7.5% (58 mmol/mol) (19) or the ADA for ages 19–25 years, with the HbA1c target as <7% (53 mmol/mol) (20). Because the protocol called for research procedures to occur at the participants’ regular diabetes clinic appointment at all clinical sites, for the vast majority of youth, the HbA1c value used in data analysis was the one measured on the day of that clinic visit when study questionnaires and interviews were conducted.

**Statistical Analysis**

The primary research questions and main objective of the data analysis plan were to describe glycemic control, self-management behavior, as well as family and demographic factors associated with D-HRQOL. This was a hypothesis-generating research design rather than a hypothesis-testing design. The sample size justification was based on the expected precision of a two-sided 95% CI for a single proportion. A global precision including all of the countries was calculated. Assuming that patient at target for HbA1c named “glycemic control” was achieved in ~40% of patients and assuming a nonreturnability rate (patients without full documentation of HbA1c) of ~5% using the capillary method, the inclusion of 500 to 1,500 patients per country/region (e.g., group of countries) allowed us to calculate two-sided 95% CI with a precision between 2.5 and 4.4% (all age groups taken into account). With a recruitment ratio of 25, 50, and 25% in the different predefined age groups of 8–12, 13–18, and 19–25 years, respectively, the precision was between 5.1 and 8.8% in the age groups 8–12 and 19–25 years and between 3.6 and 6.2% in the age group 13–18 years. If the frequency of glycemic control was <40%, the precision was better.

Outcomes are analyzed according to age group. Multivariate linear regression was used to identify patient and family characteristics associated with D-HRQOL total score. In every multivariate analysis, region and age groups were the only covariates. Multivariate linear regression was also used to identify diabetes regimen and self-management behavior characteristics associated with D-HRQOL total score (with region and age group as covariates).

**RESULTS**

**Participant and Family Characteristics**

The geographic representation of participating countries, sites, and participants is illustrated in Fig. 1. The 5,887 TEENs participants were from 6 major regions, 5 continents, over 20 countries, and 219 centers worldwide. Countries were grouped into six regions according to health care delivery systems and status as developed or developing country.

Characteristics of the global TEENs participants are reported in Table 1 and Supplementary Table 1. The mean ages of the 3 predetermined age groups (8–12, 13–18, and 19–25 years) were 10.3, 15.3, and 21.3 years, respectively. Males and females were represented equally in all three age groups. Three-fourths of the participants in each age group were Caucasian. As reported in Table 1, age at diabetes diagnosis (as a surrogate for diabetes duration) was not related to D-HRQOL.

Family factors are also reported in Supplementary Table 1 by age group and for the entire sample. Percentages of participants who lived with both parents were 85, 82, and 67% for the 8–12-, 13–18-, and 19–25-year-old groups, respectively. With respect to highest level of parental education in all three age groups, overall, ~40% of the participants’ parents had reached high-school diploma level. With respect to participant or parent having to cut back or stop work because of diabetes, 18, 11, and 9% of families cut back or stopped work for the 8–12-, 13–18-, and 19–25-year-old groups, respectively. Concerning parent involvement in diabetes management, with advancing age of the youth, the percent of parental involvement decreased as expected. Overall, 46% of youth endorsed family conflict over monitoring.
Factors Associated With Total D-HRQOL Scores in Multivariate Linear Regression
Table 1 reports demographic and family factors associated with total D-HRQOL scores (adjusted for age group and region) in a multivariate linear regression analysis.

Across all age groups, females with T1D reported lower D-HRQOL than males with T1D ($66.2 \pm 0.3$ vs. $70.2 \pm 0.3$; $P < 0.001$).

In multivariate linear regression analyses controlling for age group and region, mean total D-HRQOL scores revealed that D-HRQOL was significantly related to $\text{HbA}_1c$: the lower the $\text{HbA}_1c$, the better the D-HRQOL ($\text{HbA}_1c < 7.5\%$, D-HRQOL = 71.5 [SE 4]; $\text{HbA}_1c \geq 7.5$ to <9%, D-HRQOL = 68.4 [0.4]; and $\text{HbA}_1c \geq 9.0\%$, D-HRQOL = 64.8 [0.4]; $P < 0.001$).

Level of parental education was significantly related to D-HRQOL, with the higher the level of parental education, the better the D-HRQOL. As reported in Table 1, the presence of diabetes-specific family conflict over blood glucose monitoring was significantly related to poorer D-HRQOL ($P < 0.001$). Also, if a parent or participant had to reduce or stop working because of diabetes, the participant reported lower D-HRQOL ($P < 0.001$).

Results of analyses to explore the relationship between highest level of parental education and D-HRQOL indicated that the higher the level of education attained by the parent, the better the youth’s D-HRQOL ($P < 0.001$). Furthermore, for families in which extra income was needed to cover the medical costs of diabetes, participants reported significantly lower D-HRQOL ($P < 0.001$).

Diabetes Regimen and Self-Management Behavior Characteristics Associated With Total D-HRQOL Scores in Multivariate Linear Regression
Table 2 reports the diabetes-management characteristics associated with D-HRQOL total scores (adjusted for age group and region) in multivariate linear regression analysis. Three diabetes-management factors were significantly related to D-HRQOL: among methods used to measure food intake, advanced diet methods (e.g., carbohydrate counting compared with avoiding simple sugars) was related to better D-HRQOL ($P < 0.001$); more frequent daily blood glucose monitoring was related to better D-HRQOL ($P < 0.001$); and more days per week (3–7 compared with 0–2 days/week) in which youth had 30 min of physical activity was related to better D-HRQOL ($P < 0.001$).

CONCLUSIONS
The TEENs study has provided the largest and best-characterized evaluation of diabetes-specific quality of life in a global, contemporary sample of 8–25-year-olds with T1D to date. Results indicated that there is a linear relationship between quality of life and $\text{HbA}_1c$, with youth who attain an $\text{HbA}_1c$ target of <7.5% reporting the highest quality of life; youth with $\text{HbA}_1c > 7.5$ and <9.0% reporting significantly lower quality of life; and youth in the worst control with $\text{HbA}_1c > 9.0\%$ reporting quality of life that is significantly lower than each of the other two $\text{HbA}_1c$ groups. It is highly likely that this is a bidirectional relationship with $\text{HbA}_1c$ and diabetes quality of life interrelated. No statement of causality can be made from the TEENs cross-sectional data. A longitudinal report by Hilliard et al. (8) documented that in a sample of U.S. teens with T1D, quality of life predicted $\text{HbA}_1c$. More longitudinal studies are needed to clarify any causal
relationships between D-HRQOL and glycemic control.

Our finding that youth who report (on the PedsQL Diabetes Module 3.0) feeling more burdened by daily diabetes treatment tasks (like checking blood glucose) are characterized by checking blood glucose less frequently (as measured by medical chart review) and by poorer glycemic control (as measured by HbA1c) documents the interconnectedness of diabetes burden, self-management behaviors, and biological outcomes in this global sample of youth with T1D. These interrelationships highlight potential points for intervention—by reducing diabetes burden, youth may check blood glucose levels more frequently, which has been documented to correlate with better glycemic control (21).

With respect to D-HRQOL in the global TEENs population, it is significant that across age groups, females with T1D consistently reported lower D-HRQOL than did their male peers. This finding is consistent with results from the multinational Hvidore Study (9) as well as the SEARCH study (15) of youth with T1D in which females also reported lower D-HRQOL on the PedsQL Diabetes

| Table 1—Factors associated with D-HRQOL in multivariate linear regression |
|-----------------------------|----------------|----------------|-----------------|----------------|-------------------|
| Explanatory variable interpretation | 8–12 years | 13–18 years | 19–25 years | All | Adjusted means (SE)* Estimate (95% CI)* P value* |
| Patient characteristics | | | | | |
| Sex | | | | | |
| n | 1,715 | 2,846 | 1,326 | 5,887 | |
| Male (reference) | 51 | 52 | 51 | 51 | 70.2 (0.3) | 0.0 |
| Female | 49 | 48 | 49 | 49 | 66.2 (0.3) | −4.0 (−4.7, −3.4) | <0.001 |
| BMI (kg/m²) | | | | | 0.040 |
| n | 1,711 | 2,842 | 1,320 | 5,873 | |
| Underweight/normal (reference) | 71 | 74 | 71 | 73 | 68.7 (0.3) | 0.0 |
| Overweight | 16 | 15 | 24 | 17 | 68.7 (0.4) | 0.0 (−0.9, 0.9) | 0.942 |
| Obese | 13 | 11 | 6 | 10 | 67.3 (0.6) | −1.4 (−2.6, −0.3) | 0.012 |
| Age at diagnosis (years) | | | | | 0.010 |
| n | 1,715 | 2,846 | 1,326 | 5,887 | |
| ≥10 (reference) | 43 | 20 | 16 | 26 | 68.0 (0.4) | 0.0 |
| <6 | 49 | 33 | 25 | 36 | 69.0 (0.4) | 0.9 (0.0, 1.8) | 0.050 |
| ≥6 to <10 | 8 | 47 | 59 | 39 | 67.6 (0.4) | −0.4 (−1.2, 0.4) | 0.344 |
| HbA1c (%) | | | | | <0.001 |
| n | 1,714 | 2,846 | 1,325 | 5,885 | |
| <7.5 (reference) | 32 | 29 | 33 | 31 | 71.5 (0.4) | 0.0 |
| ≥7.5 to <9.0 | 42 | 36 | 37 | 38 | 68.4 (0.4) | −3.2 (−4.0, −2.4) | <0.001 |
| ≥9.0 | 26 | 35 | 30 | 31 | 64.8 (0.4) | −6.8 (−7.7, −5.9) | <0.001 |
| Family characteristics | | | | | 0.029 |
| Person living with patient | | | | | |
| n | 1,712 | 2,844 | 1,324 | 5,880 | |
| Living with both parents (reference) | 85 | 82 | 67 | 79 | 66.9 (0.3) | 0.0 |
| Only mother/only father | 13 | 15 | 12 | 13 | 65.7 (0.5) | 2.1 (1.1, 3.2) | 0.018 |
| Alone + other | 3 | 4 | 22 | 8 | 65.9 (0.7) | −1.1 (−2.5, 0.3) | 0.127 |
| What is the highest level of education either of the patient’s parents/guardians completed? | | | | | <0.001 |
| n | 1,673 | 2,791 | 1,274 | 5,738 | |
| Illiterate/primary (reference) | 16 | 17 | 21 | 17 | 65.2 (0.6) | 0.0 |
| Secondary | 42 | 44 | 43 | 43 | 66.0 (0.4) | 0.2 (−0.3, 1.7) | 0.165 |
| University/higher | 42 | 40 | 37 | 40 | 67.3 (0.4) | 2.1 (1.1, 3.2) | <0.001 |
| Conflict for check and interpret blood glucose levels over the past month | | | | | <0.001 |
| n | 1,706 | 2,837 | 1,314 | 5,857 | |
| Almost never (reference) | 54 | 48 | 67 | 54 | 67.8 (0.5) | 0.0 |
| Sometimes + almost always | 46 | 52 | 33 | 46 | 64.5 (0.4) | −3.2 (−4.3, −2.2) | <0.001 |
| Conflict for select and give insulin doses over the past month | | | | | 0.254 |
| n | 1,706 | 2,837 | 1,314 | 5,857 | |
| Almost never (reference) | 60 | 56 | 73 | 61 | 66.5 (0.4) | 0.0 |
| Sometimes + almost always | 40 | 44 | 27 | 39 | 65.9 (0.5) | −0.6 (−1.7, 0.5) | 0.254 |
| Has the patient or his/her family members cut down or stopped working because of diabetes? | | | | | <0.001 |
| n | 1,704 | 2,832 | 1,315 | 5,851 | |
| No (reference) | 82 | 89 | 91 | 88 | 67.5 (0.3) | 0.0 |
| Yes | 18 | 11 | 9 | 12 | 64.8 (0.6) | −2.7 (−3.7, −1.6) | <0.001 |

Data are n or n (%) unless otherwise indicated. Boldface P values indicate overall factor is significantly related to HRQOL score. *Based on N = 5,741 (5,882) for patient (family) characteristics analysis, respectively.
module. Other investigations of quality of life in youth with T1D have reported that girls with T1D reported significantly lower quality of life than did boys with T1D of the same age (22,23). Grey et al. (22) suggested that adolescent girls with T1D are more demanding of themselves than are their male counterparts. Similarly, Eiser et al. (24) reported that young adult females with T1D reported a more negative quality of life compared with young adult males with T1D. Empirical studies with youth with other chronic illnesses have also reported lower quality of life in girls. With a sample of adolescents with epilepsy, girls with high seizure severity were at highest risk for poor quality of life (25). In a sample of adolescents with chronic pain, females reported significantly lower quality of life than males (26). Furthermore, in a large study of HRQOL in healthy youth across 12 European countries, with increasing age, HRQOL declined significantly more for girls than for boys (27).

Clearly, the poorer self-reported D-HRQOL reported by adolescent girls and young adult females with T1D in the TEENs study points to an important area of marked vulnerability for adolescent and young adult females with T1D that requires increased research and improved clinical interventions.

Across all age groups, the report of diabetes-specific family conflict was significantly related to poorer D-HRQOL. This implies that clinicians should pay attention to the building up or existing presence of diabetes-specific family conflict during routine clinic visits and engage the parent and youth in discussions to diffuse the conflict and build family teamwork around diabetes management or, if the diabetes family conflict is extremely severe, to refer the family for family therapy. Mental health factors (anxiety, depression, and eating disorders) also contribute to poor D-HRQOL. In the SEARCH study, the PedsQL Diabetes Module total score was 20 points lower in youth with moderate to severe depressive symptoms compared with youth with no or minimal depressive symptoms (17).

The most important contribution of the findings reported in this study might be in the data on the significant relationships among three specific diabetes

### Table 2—Diabetes regimen and self-management behavior characteristics associated with D-HRQOL in multivariate linear regression

| Explanatory variable interpretation | 8–12 years | 13–18 years | 19–25 years | All | Adjusted means (SE)* | Estimate (95% CI)* | P value* |
|------------------------------------|------------|-------------|-------------|-----|----------------------|--------------------|---------|
| **Insulin regimen**                |            |             |             |     |                      |                    |         |
| n                                  | 1,715      | 2,846       | 1,326       | 5,887 |                      |                    | 0.100   |
| Basal bolus regimen (reference)    | 66.6       | 67.8        | 72.6        | 68.5 | 65.6 (0.7)           | 0.0                |         |
| Pump only                          | 25.6       | 24.7        | 19.5        | 23.8 | 66.5 (0.8)           | 0.8 (−0.1, 1.7)    | 0.081   |
| Any other insulin regimen          | 7.8        | 7.5         | 7.8         | 7.7  | 64.8 (0.9)           | −0.8 (−2.3, 0.6)   | 0.270   |
| **Methods used to measure food intake for diabetes management**             | <0.001     |             |             |     |                      |                    |         |
| n                                  | 1,673      | 2,760       | 1,270       | 5,703 |                      |                    |         |
| Only avoids sugars/added sugars (reference) | 11          | 10          | 9           | 10   | 63.2 (0.9)           | 0.0                |         |
| Carbohydrate counting              | 44         | 40          | 42          | 41   | 67.1 (0.7)           | 3.9 (2.4, 5.5)     | <0.001  |
| Carbohydrate exchanges/weighing/measuring | 15         | 15          | 8           | 13   | 66.3 (0.8)           | 3.1 (1.5, 4.7)     | <0.001  |
| Estimation based on experience     | 31         | 36          | 42          | 36   | 66.0 (0.7)           | 2.9 (1.4, 4.3)     | <0.001  |
| **On average in a 1-month period, about how many times per day is the participant checking his/her blood glucose with a blood glucose meter?**<sup>2</sup> | <0.001     |             |             |     |                      |                    |         |
| n                                  | 1,708      | 2,822       | 1,316       | 5,846 |                      |                    |         |
| ≤0 to ≤2 (reference)              | 13         | 23          | 40          | 24   | 63.3 (0.8)           | 0.0                |         |
| >2 to ≤4                          | 32         | 44          | 41          | 40   | 65.7 (0.7)           | 2.3 (1.3, 3.4)     | <0.001  |
| >4 to ≤5                          | 18         | 15          | 11          | 15   | 67.1 (0.8)           | 3.8 (2.5, 5.0)     | <0.001  |
| >5                                 | 38         | 18          | 8           | 22   | 66.5 (0.8)           | 3.2 (2.0, 4.5)     | <0.001  |
| **Diabetic ketoacidosis**          | <0.001     |             |             |     |                      |                    |         |
| n                                  | 1,715      | 2,845       | 1,326       | 5,886 |                      |                    |         |
| No (reference)                    | 94         | 94          | 94          | 94   | 67.3 (0.6)           | 0.0                |         |
| Yes                                | 6          | 6           | 6           | 6    | 64.0 (0.9)           | −3.2 (−4.8, −1.7)  | <0.001  |
| **Severe hypoglycemia resulting in seizure or loss of consciousness**        | 0.086      |             |             |     |                      |                    |         |
| n                                  | 1,714      | 2,845       | 1,326       | 5,885 |                      |                    |         |
| No (reference)                    | 98         | 98          | 96          | 97   | 66.6 (0.5)           | 0.0                |         |
| Yes                                | 3          | 2           | 4           | 3    | 64.7 (1.2)           | −1.9 (−4.1, 0.3)   | 0.086   |
| **Number of days when the participant spent at least 30 min doing any physical activities or exercise per week**<sup>3</sup> | <0.001     |             |             |     |                      |                    |         |
| n                                  | 1,687      | 2,812       | 1,301       | 5,800 |                      |                    |         |
| 0–2 (reference)                   | 33         | 38          | 44          | 38   | 64.5 (0.7)           | 0.0                |         |
| 3–7                               | 67         | 62          | 56          | 62   | 66.7 (0.7)           | 2.2 (1.5, 2.9)     | <0.001  |

Data are n or n (%) unless otherwise indicated. Boldface P values indicate overall factor is significantly related to HRQOL score. *Based on N = 5,460.

<sup>2</sup>Estimation based on experience 31 36 42 36 66.0 (0.7) 2.9 (1.4, 4.3) 2t o 5 38 18 8 22 66.5 (0.8) 3.2 (2.0, 4.5) 4t o 0t o 2 (reference) 33 38 44 38 64.5 (0.7) 0.0 44 40 42 41 67.1 (0.7) 3.9 (2.4, 5.5) <0.001 15 15 8 13 66.3 (0.8) 3.1 (1.5, 4.7) <0.001 31 36 42 36 66.0 (0.7) 2.9 (1.4, 4.3) <0.001 0.081 0.086 0.001 0.001 0.086 0.001
First, the self-management behaviors and D-HRQOL. A1c level of parental education was related to better D-HRQOL. With respect to other factors significantly related to D-HRQOL, lower level of parental education was related to poorer D-HRQOL; the presence of diabetes-specific family conflict was related to poorer D-HRQOL; and when a parent or participant had to reduce or stop working because of diabetes, the participant reported lower D-HRQOL. Three diabetes self-management behaviors were significantly related to better quality of life: increased frequency of daily blood glucose monitoring, use of carbohydrate counting, and greater frequency of daily self-monitoring of blood glucose.

In conclusion, in this well-characterized global cohort of 5,887 participants 8–25 years of age with T1D in the TEENs study, in each age group, the lower the HbA1c, the better the patient-reported outcome of D-HRQOL. With respect to other factors significantly related to D-HRQOL, lower level of parental education was related to poorer D-HRQOL; the presence of diabetes-specific family conflict was related to poorer D-HRQOL; and when a parent or participant had to reduce or stop working because of diabetes, the participant reported lower D-HRQOL. Three diabetes self-management behaviors were significantly related to better quality of life: increased frequency of daily blood glucose monitoring, use of carbohydrate counting, and greater frequency of daily self-monitoring of blood glucose.

Table 3—Participant self-report, D-HRQOL total score, for the eligible population

| Age Group       | Total Score (N=5,887) | Mean (SD) | 95% CI | Median | Quartiles for total score in classes are based on total eligible population. |
|-----------------|-----------------------|-----------|--------|--------|--------------------------------------------------------------------------|
| 8–12 years      | 1,690                 | 71.91 (13.18) | 71.43 | 63.39–82.14     | <61.61: 335 (19.8%) 692 (24.7%) 373 (29.6%) 1,400 (24.3%)               |
| 13–18 years     | 2,806                 | 70.09 (13.68) | 69.58 | 71.43 | ≥61.61 to <71.43: 396 (23.4%) 668 (23.8%) 317 (25.2%) 1,381 (24.0%)       |
| 19–25 years     | 1,260                 | 67.83 (14.25) | 67.05 | 71.43 | ≥71.43 to <80.36: 463 (27.4%) 739 (26.3%) 317 (25.2%) 1,519 (26.4%)       |
| Total           | 5,756                 | 67.13 (14.73) | 66.78 | 71.43 | ≥≥80.36: 496 (29.3%) 707 (25.2%) 253 (20.1%) 1,456 (25.3%)              |

Quartiles for total score in classes are based on total eligible population.

Acknowledgments. The multidisciplinary Steering Committee of the TEENs study thanks the participants and families, the study coordinators, and investigators from 219 centers in 20 countries for the efforts and commitment to this study as well as the sponsor, Sanofi Diabetes, for the financial support to perform this investigation. Duality of Interest. Funding for the TEENs study was provided by Sanofi Diabetes. B.J.A. reports participation in advisory boards for Sanofi, research support from the National Institutes of Health, JDRF, The Leona M. and Harry B. Helmsley Charitable Trust, and consultancy for Sanofi. L.M.L. reports consultancy for Eli Lilly and Company, Sanofi, Novo Nordisk, AstraZeneca, Menarini, Johnson & Johnson, LifeScan/Animas, Roche Diagnostics, Oshadi, Dexcom, and Boehringer Ingelheim. C.D. is a full-time employee of Sanofi and shareholder. T.D. reports consultancy and participation in advisory boards for Sanofi, Novo Nordisk, Eli Lilly and Company, AstraZeneca, Roche, Unomedical, and Medtronic. M.P. reports paid lecturing for Johnson & Johnson (Animas), Sanofi, Medtronic, and Roche; stock ownership in CGM3 Ltd.; participation in advisory boards for challenges in tracking a global sample of youth with T1D, the results from the cross-sectional TEENs study are important with respect to calling for prioritization of the immediate development of effective clinical interventions to optimize glycemic control and D-HRQOL of youth with T1D, especially for adolescent and young adult females with T1D.

In conclusion, in this well-characterized global cohort of 5,887 participants 8–25 years of age with T1D in the TEENs study, in each age group, the lower the HbA1c, the better the patient-reported outcome of D-HRQOL. With respect to other factors significantly related to D-HRQOL, lower level of parental education was related to poorer D-HRQOL; the presence of diabetes-specific family conflict was related to poorer D-HRQOL; and when a parent or participant had to reduce or stop working because of diabetes, the participant reported lower D-HRQOL. Three diabetes self-management behaviors were significantly related to better quality of life: increased frequency of daily blood glucose monitoring, use of carbohydrate counting, and greater number of days per week of exercise for ≥30 min. Finally, young adults, 19–25 years of age, reported lower quality of life compared with the 13–18- and 8–12-year-old groups, and females in every age group reported lower quality of life than their male counterparts, calling attention to the vulnerability to poorer D-HRQOL in young adults and females with T1D.
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