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Finnish diabetes-related quality of life questionnaire for children and adolescents: reliability and validity

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Finnish diabetes-related quality of life questionnaire for children and adolescents: reliability and validity

Abstract

Aim: To study the psychometric properties, reliability, and validity of the FinDiab quality of life questionnaire (FDQL), a strength-oriented quality of life (QOL) questionnaire for children and adolescents with type 1 diabetes (T1D). **Methods:** Participants were 215 youths with T1D (aged 10–17 years). They completed FDQL and comparison questionnaires (KINDL-R and SDQ). Demographic and disease measures were collected from the participants' medical records. The questionnaire's psychometric properties were investigated. Construct validity was studied through principal component analysis using Promax rotation, reliability with alphas, and criterion and convergent validity with correlations between sum scale, subscales, demographic and disease factors, and comparison measures. **Results:** FDQL demonstrated an adequate range of measurement and feasibility. The four-factor solution was found to be optimal, resulting in the subscales of flexibility with diabetes, well-being, social relations, and health behavior. The sum scale correlated significantly with glycemic control and the psychosocial and QOL comparison measures. Construct, criterion, and convergent validity of the subscales were also good. Children under 14 years of age reported better QOL than older adolescents. **Conclusion:** FDQL is a practical QOL assessment method focusing on strengths. The questionnaire has good validity and reliability and is easy to use as a clinical tool.

Keynotes:

- The FinDiab quality of life questionnaire was developed to assess generic and diabetes-related quality of life in youth with type 1 diabetes in a strength-oriented and positive way.
- The questionnaire is feasible and has good reliability and validity.
- Quality of life assessment at diabetes clinics helps to discuss the problems and strengths in a person-oriented way that may help the person with diabetes management.

Keywords: children and adolescents, quality of life, questionnaires, type 1 diabetes, validity

Quality of life (QOL) reflects the physical, emotional, and social aspects of personal well-being (1, 2) as well as personal health and possibility for participation in society (3). It is the person's own perception of his/her well-being and may be compromised by a chronic disease. A person's own perception of the influence of the disease — how the disease affects different areas of a person's life and what mechanisms either support or hinder disease management and treatment outcome (disease-specific health-related quality of life; HRQOL) — is crucial in medical care, and it should be acknowledged as an important outcome measure. A person-centered approach has been strengthened over the years in diabetes care along with a need to develop person-reported outcome measures (4).

Type 1 diabetes (T1D) care is a demanding part of everyday life. Peer relationships, family interaction, and family stress affect the diabetes-management and psychological well-being of both the youths with T1D and their families (5, 6). Parents are responsible for the diabetes care of young children, while during adolescence, young people themselves take on a greater responsibility for their diabetes care. The psychological well-being, life control, and good social relationships support adolescents' self-management behaviors (7). The general QOL in children and adolescents with T1D is, thus, associated with diabetes-specific HRQOL (8). In recent studies, children and adolescents with T1D have not significantly differed in terms of the HRQOL from their healthy peers (9). However, the HRQOL tends to be lower in older adolescents and in girls (9, 10). In previous studies, a better HRQOL has been associated with better treatment management in children and adolescents as measured by glycemic control (HbA1c) (10, 11).

The QOL is assessed using generic or health-related questionnaires. Several widely used QOL questionnaires have a diabetes module (e.g., PedsQL (8), KINDL-R (1, 12), Disabkids (13)). Some have been developed only for the T1D context (e.g. MIND-Youth (14), T1DAL (15)). However, some of the older questionnaires need to be updated in order to capture relevant daily actions of current diabetes management (15). In most of the previously developed QOL and HRQOL measures, items are negatively worded and problem-oriented (15), which may hinder their usability in a person-centered way in clinical practice (4). Although it has been recommended to regularly assess the HRQOL in persons with T1D (16), it is unknown how regularly the HRQOL questionnaires are used in clinics. To strengthen the focus on the HRQOL of the persons with T1D, development of an easy to use HRQOL questionnaire is needed. It can provide an additional outcome measure for the T1D management along with medical indicators.

The FinDiab quality of life questionnaire (FDQL) was developed as part of the FinDiabKids project, a nationwide program for interdisciplinary pediatric diabetes teams to improve the management of T1D in

children and adolescents in Finland. The main aim was to develop an inventory that could be used in patient care to identify both generic and diabetes-related factors that are central to a person's well-being and self-management. The second aim was to create an easy-to-use, resource-oriented tool for health care professionals in order to discuss QOL and HRQOL issues, focus on treatment, and plan the support necessary for self-management behaviors and motivation.

The FDQL questionnaire is based on the Acceptance-Commitment theory (ACT) (17), and the Strength and Resource orientation (18) as well as the previous research on the HRQOL (2, 13, 19) and psychosocial well-being of children with T1D (5-7). It has been shown that the ACT is a workable model in the management of chronic diseases because it emphasizes a person's active and flexible view of his/her own well-being (20). It has been successfully used in the treatment of various health conditions; type 2 diabetes (20), obesity (21), chronic pain (22), and depression (23). Psychological flexibility is the key concept of ACT. It has been argued to help a person to utilize his/her feelings, thoughts and behaviors in achieving optimal outcomes (24). The resource-oriented perspective is also essential in the care for chronic illnesses because it focuses on a person's resources, skills, and relationships, which support the self-management (18).

The aim of this study was to assess the reliability and validity of the FDQL questionnaire (construct validity, internal consistency, feasibility, and range of measurement), the associations of the FDQL with demographic and disease factors (criterion validity) and with comparison measures (The KINDL-R Quality of Life Questionnaire (1) and the Strengths and Difficulties Questionnaire (SDQ) (25); convergent validity). The hypothesis was that FDQL is associated with general QOL, diabetes-specific HRQOL, psychosocial wellbeing and glycemic control.

Methods

Participants and protocol

The study was a cross-sectional multi-center study. Children and adolescents with T1D (n=215), from four pediatric diabetes outpatient clinics in Finland, participated in the study. The children were eligible to participate if they were 10 to 17 years of age, if at least one year had passed since they were diagnosed with T1D, and if they could speak and read Finnish. The exclusion criteria were a cognitive developmental disability or another chronic illness (e.g., epilepsy, rheumatoid arthritis) that also affects the QOL (2).

During the visit at the outpatient clinic, the children and their guardians received information about the study and gave their written informed consent for participation. The children completed the FDQL questionnaire and one of the comparison questionnaires (either the KINDL-R, in two clinics (n=115), or the SDQ, in two clinics (n=100)), either during or after their appointments at the clinic. A healthcare professional at each of the clinics collected disease-related information from the patients' medical records. The data was collected during 2018–2019. Table 1 presents the characteristics of the study sample. Sample representativeness was evaluated through a comparison of the participating clinics with the Finnish Diabetes Association's Annual Quality Survey that is given to pediatric diabetes clinics in Finland (26). In the survey data, the participating clinics did not differ from all the pediatric diabetes clinics in diabetes care nor in patient demographics. It was not possible to select the same age range of the patients in the survey data than in the study—the survey also included children under 10 years of age. Therefore, direct comparisons cannot be made between the study and the survey data. No information was collected from those patients who declined to participate. When comparing participants completing either KINDL-R or SDQ, the only group difference was in current glycemic control; KINDL-R group had a lower mean HbA1c than the SDQ group ($t = -2.11$, $df = 213$, $p = 0.036$). The research protocol for the multi-center study was approved by the ethical review board of the Tampere University Hospital and the study was performed in accordance with the Declaration of Helsinki.

Measurements

The FinDiab quality of life questionnaire (FDQL) is a diabetes-specific HRQOL questionnaire that also includes generic QOL items. The questionnaire was created to present the QOL items in a positive, strength-oriented view. Psychologists working in pediatric diabetes clinics developed the questionnaire. The development included interviews with children and adolescents with T1D, their families and the personnel of diabetes clinics on the core factors related to the daily living with diabetes, and the usability, understanding and acceptability of the questionnaire. The questionnaire was piloted in three clinics by youth with T1D (n=20) during 2017–2018. The questionnaire was revised according to the comments of the patients and staff. The informants reported that the positive direction of all statements simplified both answering and scoring, making the questionnaire easy to complete. From the original 28 items, 2 were deleted due to redundancy, and 3 were revised for clarity. The final questionnaire included 26 items that focused on the daily living with T1D and assessed the QOL in terms of emotional and physical well-being, school, friendship, family, diabetes management, diabetes discussion, and coping with diabetes.

The child was asked to evaluate the items based on the events of the past week. Each item (e.g., I have managed to take good care of my diabetes) is rated on a 5-point Likert scale. Higher scores demonstrate a better QOL. The sum score of the scale ranges from 0 to 104. It takes five to ten minutes to complete the questionnaire. There were 12 individuals who had one missing item on the scale. Those missing items were replaced with the mean of the individual's scale score.

The KINDL-R Quality of Life Questionnaire (1) is a methodologically and psychometrically suitable generic and health-related QOL instrument used for children and adolescents 3 to 17 years of age. We used a generic module of the questionnaire, consisting of 24 questions (including the physical, psychological, self-esteem, family, friends, and school-related QOL), an illness-related module, consisting of 6 questions, and a diabetes module, consisting of 17 diabetes-specific questions. The answers were given on a Likert scale from 1–5. The generic subscales were combined to form a total score of maximum 120, with higher scores indicating a better QOL. The maximum score in the illness module was 20 and 85 in the diabetes-specific module. For the analysis, the scores were scaled to be from 0 to 100 points. For children 10 to 13 years of age, we used the Kid-KINDL children's version of the questionnaire and, for the youth 14 to 17 years of age, the Kiddo-KINDL adolescent's version, which had the same constructs and items but more age-appropriate wordings. For the analyses, the items of the two questionnaires were combined. The KINDL-R has widely been used in research and has good reliability and validity (1). In this study, 17 of 115 children did not answer the illness module due to misunderstanding the scale instructions. Therefore, the illness scale was omitted from the analyses. Other scales had sporadic missing values that were replaced with the mean of the individual's subscale score. The Cronbach's alpha was 0.86 for the KINDL-R generic scale and 0.88 for the diabetes scale.

The Strengths and Difficulties Questionnaire (SDQ; 25) is a 25-item questionnaire that assesses child behavior and mental well-being. It includes subscales for emotional problems, conduct problems, hyperactivity, peer problems, and prosocial behavior. These subscales consist of 5 items each, which are rated on a Likert scale from 0–2. The total difficulties score is calculated by summing all the problem subscales (except for the prosocial scale). Cronbach's alpha for the SDQ was 0.71 (subscales ranging between 0.63 for the prosocial behavior subscale and 0.33 for the conduct problems subscale).

Demographic and diabetes measures

Demographic (gender and age) and diabetes-related data (age at diagnosis, most recent HbA1c, treatment type, use of glucose sensor, and episodes of severe hypoglycemia and ketoacidosis during the past year) were collected from the patients' medical records.

Data analysis

Analyses were conducted using IBM SPSS Statistics (version 25.0 and 26.0; IBM SPSS, Chicago, Illinois) and overall confirmatory factor analysis model fit indices were carried out using Stata/SE 15.1 for Windows (StataCorp. 2019. Stata Statistical Software: Release 15. College Station, TX: StatCorp LP).

The construct validity of the FDQL questionnaire was studied using principal component analysis (PCA) with Promax rotation. The exploratory factor analysis was based on subscale factor loadings at least 0.4. PCA revealed the presence of four subscales with an eigenvalue greater than 1. The Kaiser-Meyer-Olkin measure of sampling adequacy tested whether the partial correlations among questions were small.

The internal consistency of the FDQL was studied using Cronbach's alphas for the subscales and for the entire questionnaire. Alpha scores of > 0.70 were considered acceptable.

The feasibility of the FDQL was studied by determining the percentage of missing items. Missing $< 2\%$ of data was considered acceptable (27). The range of measurement was analyzed using the percentage of the sum scores, reaching upper or lower end of the scale. The lower percentages ($< 15\%$) of extreme scores were considered to be satisfactory for the measurement (28).

The criterion validity—e.g., the associations between the FDQL questionnaire scores, disease factors, and demographic factors—was studied using Pearson product moment correlations, t-tests, and one-way ANOVAs. In addition, the comparisons between the FDQL scores of younger (10–13 years of age) and older (14–17 years of age) children were analyzed using t-tests and Pearson chi-square tests.

The convergent validity was assessed using the Pearson product moment correlations between the FDQL questionnaire and the comparison questionnaires (KINDL-R, SDQ). The hypothesis was that the FDQL sum scale correlated with the general QOL, illness- and diabetes-related QOL and psychosocial wellbeing, and the subscales correlated with similar subscales of the comparison measures. Because the comparison questionnaires assessed slightly different concepts than the FDQL, medium effect size (> 0.30) for correlations was considered acceptable.

Results

Total of 215 adolescents (47.4 % girls) with mean age 13.5 years participated to the study. Mean age at diagnosis of TD1 was 7.12 years. More detailed demographic and diabetes related background data is presented in Table 1.

Construct validity

The FDQL questionnaire items, frequencies, and statistics are presented in Table 2. The item means ranged from 2.70 to 3.60. The principal component analysis with Promax rotation and Kaiser normalization for the 1-factor solution explained 35% of the variance. A satisfactory factor structure with original 26 items indicates that 4 main components explained 55% of the variance. The communalities of all items were considered tolerable, ranging $h^2 = 0.304\text{--}0.770$. The items in the 4-factor solution had considerably high loadings (Table 3), exceeding $\lambda = 0.400$, except for item 7 ($\lambda > 0.300$). The Kaiser-Meyer-Olkin measure of sampling adequacy was meritorious 0.898, Bartlett's test of sphericity (2728.30, $df = 325$, $p < 0.001$). The overall model fit index was mediocre (RMSEA = 0.078 [90% CI = 0.070, 0.086], CFI = 0.849). We also explored alternative models with both 4 factors (but without item 7) and with 3 factors (without the health behavior factor) but the models did not reach significantly higher fit indices (RMSEA = 0.081 [90% CI = 0.073, 0.089], CFI = 0.849; RMSEA = 0.082 [90% CI = 0.074, 0.091], CFI = 0.860, respectively). Therefore, the original 4-factor solution, which was suitable for the theoretical background, was used as the model. The subscales of flexibility with diabetes, well-being, social relations, and health behavior were derived from these 4 factors. In addition, the sum scale for the questionnaire was calculated.

Internal consistency

Cronbach's alpha was 0.92 for the sum scale with all the items and 0.87 for the flexibility with diabetes subscale, 0.87 for the well-being subscale, 0.74 for the social relations subscale, and 0.58 for the health behavior subscale. Because internal consistency in the health behavior subscale was low and included only 3 items, it was not used as a separate subscale but was included in the sum score.

Feasibility was studied by determining percentage of missing items (Table 2). There were only a few sporadic, missing items in the FDQL questionnaire. Only 0.2% of all possible answers were missing, ranging from 0 to 1.4% between the items, which is considered to be acceptable (27).

Range of measurement

The items and scales tended to be evaluated positively, with only a few “Never” responses (Table 2). There were no “Never” responses for 6 items and no “Rarely” responses for 2 items. For the sum scale, the values ranged from 34 to 103 (the possible range being 0–104). The range for the flexibility with diabetes subscale was 5–28 (the possible range being 0–28), while it was 6–44 for the well-being subscale (the possible range being 0–44) and 10–24 for the social relations subscale (the possible range being 0–24). The sum score did not reach neither the upper nor the lower end of the scale. In the flexibility with diabetes subscale, 12.6 % reached the upper end of the scale. For the well-being subscale, 0.5% participants reached the upper end of the scale and for the social relations subscale 8.4% did so. The range of the measurement was considered to be satisfactory (28).

Criterion validity

The means of the FDQL questionnaire, the demographic and disease measures, and the comparison questionnaires in the entire study group and in the subgroups of younger and older children are presented in Table 1. The correlations between the FDQL, the demographic and disease measures, and the comparison questionnaires are presented in Table 4. Better glycemetic control was positively associated with the FDQL sum scale, the flexibility with diabetes subscale, and, with a small effect size, with the well-being subscale. Younger age was positively associated with the flexibility with diabetes subscale. On the other hand, older age was associated with a higher score on the social relations subscale. There were no significant differences in FDQL scores according to the treatment type or the history of severe hypoglycemia or ketoacidosis.

The only gender difference in FDQL scores occurred on the flexibility with diabetes subscale ($F(1, 214) = 4.49, p = 0.035$), with boys obtaining higher scores. When comparing the 10–13-year-old and 14–17-year-old subgroups the members of the younger age group had been younger when diagnosed with T1D and had better glycemetic control. The younger age group also had higher scores on the FDQL sum scale as well as on the flexibility with diabetes and well-being subscales. On the contrary, the groups did not differ in the SDQ psychosocial well-being and the KINDL-R generic QOL, except that the younger children reported poorer family-related QOL (Table 1).

Convergent validity

FDQL sum score and well-being score were significantly correlated with all the subscales of the comparison measures with medium to large effect sizes. In addition, the flexibility with diabetes subscale

showed significant positive correlations with the generic QOL and diabetes scales of the KINDL-R and negative correlations with the problem subscales of the SDQ, while the social relations subscale showed significant positive correlations with the social and generic QOL scales of the KINDL-R, indicating good convergent validity (Table 4).

Discussion

The FinDiab Quality of Life questionnaire was developed as a practical tool for assessing the generic QOL and diabetes-specific HRQOL in clinical practice. This study demonstrated that the questionnaire has good psychometric properties (e.g. reliability) and that its subscales are comprehensible, with good construct and convergent validity. In addition, the QOL as measured by the questionnaire was associated with glycemic control, which is regarded to be the best measure of diabetes care.

The FDQL sum scale was strongly associated with glycemic control but not with treatment type or history of diabetes complications. Previous studies have related glycemic control to the diabetes-related QOL (10, 11). Lawrence et al. (11) found that having a history of diabetes complications was associated with a poorer HRQOL, which is contrary to our findings. The FDQL sum scale demonstrated associations with the generic QOL, diabetes-specific HRQOL, and psychosocial well-being, with medium to large effect sizes, indicating good convergent validity as a QOL measurement.

The FDQL questionnaire adds a new perspective to the existing QOL questionnaires by covering key aspects of Acceptance-Commitment (e.g. flexibility) and Strength and Resource approach (e. g. social relations and support). As such, it helps the clinician when discussing the different domains of life with diabetes in a person-centered, strength-oriented way (4).

Of the four subscales, flexibility with diabetes captured the Acceptance-Commitment orientation, with the ability to accept diabetes and self-care as part of daily life and the ability to handle tasks. It was strongly related to glycemic control and to the generic and diabetes-related QOL, as also found in previous studies (20, 24). Interestingly, younger children experienced better flexibility than older adolescents. This probably reflects the higher demands of the more independent self-care of older adolescents (29). The well-being subscale measured the QOL in terms of physical and emotional well-being as well as the possibility of participation in school and leisure activities. It showed good convergent validity in psychosocial well-being and the generic QOL, which is in accordance with the previous studies (9, 11). However, it was not strongly associated with glycemic control. The social relations subscale

measured interpersonal relationships and their resources in diabetes management. It had the strongest associations with psychological well-being, prosocial behavior, and the generic QOL. Older adolescents reported better social relations than younger children. The health behavior subscale captured important aspects of sleep, nutrition, and exercise in diabetes care and well-being but, as a three-item subscale, its reliability was insufficient for consideration as an independent subscale. The construct of the FDQL scale was in accordance with the theoretical background, however, the health behavior factor was problematic for the statistical model.

The reliability and validity of the FDQL questionnaire were studied using a representative sample in regarding diabetes care and patient demographics. Unfortunately, we could not compare the study sample directly with the Finnish survey sample – the survey also included children under 10 years of age. As a limitation, we did not assess the relationship between FDQL and diabetes self-management behaviors although it would have brought important information on the convergent validity. In addition, we only used self-reports. The use of parental ratings, along with the reports of the children, would have provided additional information. However, the parental reports of their children's QOL tend to be more negative than the children's own perceptions (30). Interestingly, some children failed to rate the illness scale on the KINDL-R, despite being instructed to rate the items if they had been treated in a hospital or had a chronic disease. Perhaps the children regarded themselves as healthy—i.e., did not regard diabetes as a chronic disease or thought that the questions referred to some disease other than diabetes. This resulted in missing data, which is clearly a limitation of this study. Reliabilities in some of the SDQ subscales were low in our sample. The SDQ is used in primary health care as a screening measure, and it assess problems in psychosocial well-being. Perhaps the low percentage of problem behavior in the youth with diabetes in this study indicates that the questionnaire is not the first choice when supporting self-management of a person with T1D. However, it may be utilized as an additional screening tool in those with suspected psychosocial concerns.

To conclude, the FDQL questionnaire seemed to be simple to complete and the children missed very few items, indicating the feasibility of the measure. Although the positively-worded items might direct toward an overly positive response style, the range of measurement was adequate and the questionnaire had a sufficient range to differentiate the children with a lower QOL. On the other hand, the questionnaire was designed to present the QOL in a positive and resource-oriented approach in order to promote person-oriented approach at clinics. FDQL can be used as a qualitative instrument to identify the problems and strengths that a person with diabetes experience in his/her life and to discuss the intervention

possibilities based on this patient report. The questionnaire is suitable for a standard annual follow-up for measuring the generic and diabetes-related QOL in school-age children and adolescents. Besides the clinical use, FDQL can be used in research, and it is suitable for international use when translated.

List of abbreviations: FDQL the FinDiab Quality of Life questionnaire; QOL quality of life; HRQOL health-related quality of life; T1D type 1 diabetes; SDQ the Strengths and Difficulties Questionnaire; KINDL-R the Revised Children's Quality of Life Questionnaire; ACT Acceptance-Commitment theory; HbA1c glycemic control; MDI multiple daily insulin injections; CSII continuous subcutaneous insulin infusion; DKA diabetic ketoacidosis; PCA principal component analysis

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Conflict of interest: none

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Table 1. Demographic and medical background data, and psychosocial and QOL characteristics of the entire study group as well as of the younger and older age groups. Either t-test or Pearson chi-square test were used for the age-group comparisons.

	Study Group			t / chi ²	p
	All	10–13 years	14–17 years		
Number of participants	215	114	101		
Age (years); mean (SD)	13.54 (1.95)	12.01 (1.21)	15.27 (.87)	-22.88	0.000
Gender; % girls	47.4	43.9	51.5	1.25	0.264
Age at diagnosis (years); mean (SD)	7.12 (3.52)	6.38 (3.14)	7.95 (3.75)	-3.34	0.001
Latest HbA1c (mmol/mol); mean (SD)	64.8 (12.3)	62.6 (12.4)	66.6 (13.6)	-2.30	0.023
Treatment type; %				1.05 [†]	0.591
MDI	64.7	63.2	66.3		
CSII	34.9	36.0	33.7		
Other	0.5	0.9	0.0		
Use of Glucose Sensor; %	96.7	95.6	98.0	0.98	0.321
Severe hypoglycemia; %	9.3	11.4	6.9	3.06	0.383
DKA; %	1.9	2.6	1.0	1.13	0.570
FDQL, n	215	114	101		
FDQL sum score mean (SD)	80.95 (11.96)	82.50 (11.21)	79.21 (12.58)	2.03	0.044
FDQL Flexibility with diabetes mean (SD)	22.48 (4.76)	23.38 (3.78)	21.48 (5.52)	2.91	0.004
FDQL Well-being mean (SD)	30.07 (5.16)	30.83 (4.62)	29.21 (5.61)	2.33	0.021
FDQL Social relations mean (SD)	19.48 (3.18)	19.21 (3.39)	19.78 (3.18)	-1.32	0.188
SDQ, n [†]	100	54	46		
SDQ Emotional problems mean (SD)	2.49 (1.93)	2.35 (1.87)	2.65 (2.01)	-0.77	0.441
SDQ Conduct problems mean (SD)	1.82 (1.24)	1.80 (1.34)	1.85 (1.14)	-0.21	0.837
SDQ Hyperactivity mean (SD)	2.93 (1.84)	3.06 (1.88)	2.78 (1.81)	0.74	0.463
SDQ Peer problems mean (SD)	1.73 (1.65)	1.61 (1.60)	1.87 (1.72)	-0.78	0.438
SDQ Prosocial behavior score mean (SD)	7.86 (1.56)	7.80 (1.61)	7.93 (1.51)	-0.44	0.660
SDQ Total difficulties mean (SD)	8.97 (4.75)	8.81 (4.95)	9.15 (4.55)	-0.35	0.725
KINDL-R, n [†]	115	60	55		

KINDL-R Generic QOL mean (SD)	77.92 (8.60)	78.17 (8.36)	77.65 (8.92)	0.32	0.750
KINDL-R Physical mean (SD)	78.09 (13.39)	78.83 (13.19)	77.27 (13.67)	0.62	0.535
KINDL-R Psychological mean (SD)	82.09 (9.15)	83.17 (9.16)	80.91 (9.08)	1.33	0.188
KINDL-R Self-esteem mean (SD)	71.35 (14.09)	72.42 (12.23)	70.18 (15.90)	0.85	0.398
KINDL-R Family mean (SD)	84.43 (10.59)	82.08 (11.51)	87.00 (8.90)	-2.57	0.011
KINDL-R Friends mean (SD)	79.74 (10.82)	78.50 (10.67)	81.09 (10.92)	-1.29	0.201
KINDL-R School mean (SD)	71.97 (14.96)	74.00 (13.68)	69.72 (16.09)	1.53	0.128
KINDL-R Diabetes mean (SD)	78.16 (12.94)	78.09 (12.67)	78.22 (13.34)	-0.05	0.957

QOL quality of life; HbA1c glycemic control; MDI multiple daily insulin injections; CSII continuous subcutaneous insulin infusion; DKA diabetic ketoacidosis; FDQL the FinDiab Quality of Life questionnaire; SDQ the Strengths and Difficulties Questionnaire; KINDL-R the Revised Children's Quality of Life Questionnaire; † two clinics; ‡ One-way ANOVA.

Table 2. The FDQL questionnaire; response frequencies (%), item statistics, and missing values (%).

Item	Response frequency %					Mean (SD)	Missing values %
	0 never	1 rarely	2 sometimes	3 often	4 always		
1. I have been in a good mood.	0.5	1.4	9.3	73.5	15.3	3.01 (0.593)	0.0
2. It has been easy for me to calm down and concentrate.	0.9	3.3	22.8	53.0	20.0	2.89 (0.789)	0.0
3. I have succeeded in my activities.	0.9	0.5	14.0	69.3	14.0	2.96 (0.632)	1.4
4. I have been satisfied with my life.	0.5	1.9	12.1	45.6	40.0	3.21 (0.770)	0.0
5. I have felt active and brisk.	1.9	3.3	31.2	44.2	19.5	2.76 (0.875)	0.0
6. I have been feeling healthy.	0.9	5.1	11.6	53.0	29.3	3.03 (0.847)	0.0
7. I have fallen asleep easily and have slept well.	1.4	4.2	22.8	43.7	27.9	2.93 (0.878)	0.0
8. I have exercised and been outdoors.	1.4	2.8	26.0	43.7	27.9	2.90 (0.875)	0.5
9. I have eaten regularly.	0.5	5.1	13.5	46.5	34.4	3.09 (0.851)	0.0

10. It has been nice at school.	2.3	6.5	25.6	47.0	18.6	2.76 (0.904)	0.0
11. My studies have gone well.	1.9	4.2	19.1	55.3	19.5	2.86 (0.851)	0.0
12. I have had interesting things to do.	0.5	3.7	13.5	57.2	25.1	3.03 (0.760)	0.0
13. I have gotten along well with my friends.	0.0	0.0	3.7	36.7	59.5	3.57 (0.562)	0.0
14. I have gotten along well with my family.	0.0	0.5	13.5	40.9	45.1	3.33 (0.714)	0.0
15. My parents have understood and supported me.	0.0	2.8	8.8	39.1	49.3	3.37 (0.749)	0.0
16. We have talked about my diabetes at home.	2.3	9.3	24.2	45.6	18.1	2.70 (0.940)	0.5
17. It has been easy to talk with my friend about diabetes.	2.3	9.8	11.6	37.7	38.6	3.03 (1.019)	0.0
18. I know what tasks in my diabetes care I should conduct by myself.	0.0	0.9	3.3	30.7	65.1	3.60 (0.609)	0.0

19. I have managed to handle my diabetes well.	1.9	6.0	15.8	46.0	29.8	2.97 (0.935)	0.5
20. I have been able to do things that are important to me despite having diabetes.	0.0	0.5	8.4	35.3	55.8	3.47 (0.662)	0.0
21. I have been able to live a good life with my diabetes.	1.4	2.8	11.2	37.7	45.6	3.27 (0.861)	1.4
22. Blood glucose measurements and insulin adjustments have gone well.	1.9	5.1	14.4	47.0	31.6	3.01 (0.928)	0.0
23. I have gotten along well with my diabetes at home.	0.5	1.9	9.3	39.3	49.1	3.34 (0.777)	0.5
24. I have gotten along well with my diabetes at school.	1.4	3.3	13.0	40.9	40.9	3.18 (0.885)	0.5
25. I have gotten along well with my diabetes during hobby and leisure time.	1.4	1.9	10.7	40.0	45.6	3.25 (0.845)	0.5

26. My parents and other adults have supported me if I needed help with diabetes treatment.	0.0	0.0	7.0	32.6	60.5	3.54 (0.623)	0.0
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To use this questionnaire, please contact the first author.

Table 3. Factor loadings of the FDQL questionnaire items, according to principal component analysis with Promax rotation.

Item	Factors			
	Flexibility with diabetes	Well-being	Social relations	Health behavior
1. I have been in a good mood.		0.735		
2. It has been easy for me to calm down and concentrate.		0.714		
3. I have succeeded in my activities.		0.700		
4. I have been satisfied with my life.		0.551		
5. I have felt active and brisk.		0.546		
6. I have been feeling healthy.		0.552		
7. I have fallen asleep easily and have slept well.				0.344
8. I have exercised and been outdoors.				0.772
9. I have eaten regularly.				0.545
10. It has been nice at school.		0.825		
11. My studies have gone well.		0.688		
12. I have had interesting things to do.		0.444		
13. I have gotten along well with my friends.		0.597		
14. I have gotten along well with my family members.			0.541	
15. My parents have understood and supported			0.575	

me.				
16. We have talked about my diabetes at home.			0.780	
17. It has been easy to talk with my friend about diabetes.			0.668	
18. I know what tasks in my diabetes care I should conduct by myself.			0.655	
19. I have managed to handle my diabetes well.	0.815			
20. I have been able to do things that are important to me despite having diabetes.	0.663			
21. I have been able to live a good life with my diabetes.	0.675			
22. Blood glucose measurements and insulin adjustments have gone well.	0.895			
23. I have gotten along well with my diabetes at home.	0.876			
24. I have gotten along well with my diabetes at school.	0.846			
25. I have gotten along well with my diabetes during hobby and leisure time.	0.800			
26. My parents and other adults have supported me if I needed help with diabetes treatment.			0.513	

Table 4. Pearson correlations between the FDQL, demographic, disease, and comparison questionnaires.

	FDQL sum score	FDQL Flexibility with diabetes	FDQL Well-being	FDQL Social relations
FDQL sum score	1			
FDQL Flexibility with diabetes	0.835***	1		
FDQL Well-being	0.881***	0.607***	1	
FDQL Social relations	0.670***	0.393***	0.438***	1
Age	-0.102	-0.191**	-0.121	0.150*
Age at diagnosis	-0.041	0.026	-0.130	0.103
Latest HbA1c	-0.289***	-0.448***	-0.149*	-0.064
SDQ Emotional problems	-0.459***	-0.244*	-0.449***	-0.361***
SDQ Conduct problems	-0.401***	-0.345***	-0.372***	-0.215*
SDQ Hyperactivity	-0.396***	-0.207*	-0.424***	-0.266**
SDQ Peer problems	-0.294**	-0.194	-0.235*	-0.224*
SDQ Prosocial behavior	0.331**	0.132	0.391***	0.276**
SDQ Total difficulties	-0.548***	-0.337**	-0.526***	-0.385**
KINDL-R Generic QOL	0.801***	0.617***	0.824***	0.451***
KINDL-R Physical	0.508***	0.369***	0.558***	0.224*
KINDL-R Psychological	0.620***	0.525***	0.616***	0.303**
KINDL-R Self-esteem	0.676***	0.553**	0.753***	0.266**
KINDL-R Family	0.415***	0.245**	0.324***	0.529***
KINDL-R Friends	0.413***	0.251**	0.449***	0.312**
KINDL-R School	0.699***	0.590***	0.706***	0.324***
KINDL-R Diabetes	0.542***	0.566***	0.469***	0.252**

FDQL the FinDiab Quality of Life questionnaire; HbA1c glycemic control; SDQ the Strengths and Difficulties Questionnaire; KINDL-R the Revised Children's Quality of Life Questionnaire.

* $p < .05$, ** $p < .01$, *** $p < .001$