Health-Related Quality of Life Among German Youths With Early-Onset and Long-Duration Type 1 Diabetes

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OBJECTIVE—To evaluate self- and parent reports of general health status and health-related quality of life (QoL) in children and adolescents with early-onset and long-lasting type 1 diabetes compared with the general population in Germany.

RESEARCH DESIGN AND METHODS—A total of 629 subjects aged 11 to 17 years, with a type 1 diabetes onset occurring from age 0 to 4 years during the years 1993–1999, and their parents, completed questionnaires, including the generic KINDL-R Questionnaire for Measuring Health-Related Quality of Life in Children and Adolescents, revised version, to assess QoL. The comparison group ($n = 6,813$) was a representative sample from the German Health Interview and Examination Survey for Children and Adolescents (KiGGS) study. Regression analyses were conducted using sociodemographic and health-related covariates.

RESULTS—Intensified insulin therapy was used to treat 93% of children and adolescents with type 1 diabetes. They reported "excellent" general health as often as peers (adjusted OR 0.83 [95% CI 0.66–1.04] for an "excellent" rating), but the parent-rated general health was worse than that in the general population (OR 0.60 [0.48–0.74]). The patients reported increased self-esteem (adjusted difference $\beta = 4.39$ [SE 0.82]; $P < 0.001$) and well-being at school ($\beta = 3.41$ [0.77]; $P < 0.001$) but lower well-being within their families ($\beta = -2.42$ [0.80]; $P = 0.002$). The self- and parent-reported total QoL did not differ between the patient group and the general population. The adjusted difference (SE) between the two samples in total QoL was $\beta = 0.89$ (0.52; $P = 0.087$) in the self-reports and $\beta = -0.98$ (0.53; $P = 0.066$) in the parent-reports.

CONCLUSIONS—Compared with the general population, the QoL and general health status were not impaired among those aged 11–17 years with early-onset type 1 diabetes, despite the challenges of modern therapy.

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E arly-onset type 1 diabetes is a chronic metabolic disorder with a continuously rising incidence in Germany and many other countries, in particular among 0- to 4-year-old children, with a predicted doubling of cases in Europe between 2005 and 2020 (1,2). To ensure normal physical growth and development and to prevent acute and late diabetes complications, life-long continuous self-management is necessary. Complex treatment regimens (3) and awareness of possible diabetes complications can affect the lives of patients and their families and cause psychosocial problems (4). In turn, adverse psychosocial conditions may increase the risk of poor self-management and deterioration of glycemic control (5,6). A major goal of pediatric diabetes care is to achieve near-normal glycemic control without a significant impairment in the quality of life (QoL). The health-related QoL has been increasingly recognized as an important health indicator for children in the general population and in those with chronic conditions, such as type 1 diabetes (7). Wallander et al. (8) defined QoL as well-being in multiple domains of life considered salient in one's culture and time. By using QoL measurements with a generic approach, direct comparisons of populations with different states of health are possible (8). It is recommended that self-reported QoL data be complemented by proxy-ratings. Parents' perceptions of their children's disease and the effects of the disease on daily life can provide important complementary information (9–11). The World Health Organization recommends the self-assessment of health by a very general and simple question as a principal indicator (12).

Several studies have already analyzed the QoL of youths with type 1 diabetes compared with peers, and findings were not consistent (13–21). Previous studies that used the Pediatric Quality of Life Inventory (PedsQL) to measure generic QoL and compared the type 1 diabetic sample with healthy peers observed worse QoL reported by patients (13), by both patients and parents (14), or only by parents (15,16). Studies that analyzed generic QoL measured by the Questionnaire for Measuring Health-Related Quality of Life in Children and Adolescents, revised version (KINDL-R) did not observe impaired self-reported QoL among youths with type 1 diabetes (17,18). Another study reported an even higher total QoL (measured by a self-designed questionnaire) among youths with type 1 diabetes than among healthy control subjects (19). In studies using the Child Health Questionnaire, youths with type 1 diabetes did not differ from peers, except for a lower rating on the general health scale (20,21), but parent-reported functional health and well-being was worse (21). The QoL of youths with early-onset diabetes, beginning between the ages of 0 and 4 years and already continuing for 10 or more years, is largely unexplored.

The aim of this study was to compare the self- and proxy-reported general health status and multidimensional generic QoL in youths with early-onset and long-lasting

type 1 diabetes with data from representative normal peers.

RESEARCH DESIGN AND METHODS

Data sources

Data from the baseline survey (2009–2011) of the nationwide, population-based cohort study, "Clinical Course of Type 1 Diabetes in Children, Adolescents and Young Adults with Disease Onset in Preschool Age" (diabetes study), were used. The study was approved by the responsible commissioner for data protection and the ethics committee of Düsseldorf University. The baseline survey was a questionnaire survey for 11- to 21-year-old subjects with an onset of disease during the period of 1993 to 1999, when the patients were younger than 5 years of age. The patients were selected from the nationwide diabetes register at the German Diabetes Center (DDZ), which has anonymously recorded incident cases since 1993 (22). For registrations of new cases of type 1 diabetes, the DDZ register uses three data sources: a nationwide hospital-based active surveillance system (called ESPED), annual inquiries among medical practices, and the nationwide DPV database for the prospective documentation of diabetes care in Germany (23). Overall, the DDZ diabetes register is estimated to be ~95% complete.

The selected sample comprised 3,270 patients. For 3,178 patients, at least one treatment center or facility (hospital or medical practice) that reported the respective patient to the diabetes register could be identified, and they were requested to forward the study documents to the (former) patients. Between September 2009 and December 2010, 2,241 patients received the questionnaires along with information about the study and a consent form. Finally, comprehensive questionnaires and informed consent from 840 subjects aged 11 to 21 years were returned to the study center, and an additional 280 patients/parents answered short questionnaires. The overall response rate for the study was 50%. The response rate for the comprehensive questionnaires was 43% among 11- to 13-year-old subjects and 42% among 14- to 17-year-old subjects.

Before data entry, the incoming questionnaires were checked for completeness and plausibility; attempts were made to clarify incomplete or unclear data by telephone or mail to minimize the missing data. Additional measures that were implemented to ensure high data quality included double-coding and the entry of data by two different staff members, routine data synchronization and correction where required, and plausibility controls.

The potential selection bias with respect to age, sex, age at diabetes onset, and diabetes duration was assessed by comparing the subsample covered by the final study database ($n = 840$) with the sample not covered ($n = 2,430$). Participants and nonparticipants did not differ by sex, but the participants were on average significantly ($P < 0.001$) younger (0.8 years), had an earlier disease onset (0.2 years), and had a shorter duration of disease (0.6 years).

The Public Use File of the German Health Interview and Examination Survey for Children and Adolescents (KiGGS 2003–2006, Robert-Koch-Institute, Berlin, Germany), a representative nationwide survey, was used as the normative data. The data were collected from May 2003 to May 2006 in the baseline survey of the KiGGS. The survey's target population was noninstitutionalized children and adolescents aged 0–17 years and living in Germany. The overall response rate for the KiGGS was 67% (69% in 11- to 13-year-old subjects and 63% in 14- to 17-year-old subjects). The final sample included 17,641 participants. A detailed description of the survey has been previously published (24).

Both of the studies used extensive, standardized, self-administered questionnaires to obtain information from the parents, as well as from the children and adolescents. The questionnaires used in the diabetes study were identical to those used in the KiGGS whenever possible and contained additional questions to collect information regarding diabetes. The participants in the diabetes study answered the mailed questionnaires at home; the participants in the KiGGS responded to the questionnaires at the study centers.

The study population

The inclusion criteria for the patient group were newly diagnosed with type 1 diabetes between the ages of 0 and 4 years and within the years 1993–1999 in Germany, and participation in the comprehensive questionnaire survey between the ages of 11 and 17 years together with their parents. The criteria were fulfilled by 629 patients. The inclusion criterion for the comparison group was participation in the baseline KiGGS between the ages of 11 and 17 years. The criterion was fulfilled by 6,813 youths and their parents.

Variables

The outcome measures were the self-reported general health status and QoL, as well as the parents' ratings of their children's general health status and QoL. The general health status was assessed with the question, "How would you describe your/your child's health in general?" with a 5-point Likert scale (excellent, good, moderate, poor, very poor). The wording was identical to the question used in the KiGGS (25).

The KINDL-R was used to measure QoL in the diabetes study and in the KiGGS. The KINDL-R questionnaire takes a generic approach and comprises 24 items to which the participants are asked to respond on a 5-point Likert scale (never, seldom, sometimes, often, all the time). The 24 items cover six dimensions: physical well-being, emotional well-being, self-esteem, family, friends (social contacts), and school (everyday functioning). The subscales of these six dimensions were combined to form a total score, in accordance with the manual (26). The subscale scores and the total score were calculated so that a higher score corresponded to a higher QoL and then transformed to reflect a range between 0 and 100. The KINDL-R was evaluated to be a methodologically suitable, psychometrically sound, and flexible measure to assess the QoL in children and adolescents (27–29). Self- and proxy-report versions showed factorial, convergent, discriminant, and known-groups validity (11). Children and adolescents answered the version Kiddo-KINDL-R. The Parents' Questionnaire KINDL-R was used for proxy-ratings.

The covariates included demographic and health-related data. Demographic data included age, sex, residence in West or East Germany, information about the family structure, informant of the proxy-report, immigrant background, and socioeconomic status. Participants were classified as having an immigrant background if they had emigrated from another country and at least one of their parents was not born in Germany or was of non-German nationality. Socioeconomic status was defined as low, intermediate, or high according to the total scores of the composite social status index, which integrated information obtained from the parents' questionnaires about parental education level, professional status, and household income (24,25).

The health-related data included the occurrence of hospitalization during the

past 12 months, as well as the weight and height (self-reported in the diabetes study, standardized measurement in the KiGGS) to calculate the BMI (kg/m^2). The BMI was classified as underweight, normal weight, or overweight according to Kromeyer-Hauschild et al. (30).

Additional information compiled about the patients included the age at the onset of diabetes, the duration of diabetes at the time of the follow-up, the HbA_{1c} (average of self- and proxy-reports based on local measurements), and the insulin regimen.

Statistical analyses

The descriptive statistics are reported as percentages or means and SDs. To ensure that the comparison group was representative of the population, all analyses of the KiGGS were weighted with a survey-weighting factor as recommended, taking into consideration the differences in demographic characteristics between the survey respondents and the general German population (31). All analyses were performed with SAS 9.2 software (SAS Institute, Cary, NC).

Multivariable logistic regression was applied for the outcome variable of general health status to identify differences between the two study populations in the self- and proxy-reports as well as the disagreement between self- and proxy-reports. The response option "excellent" was tested against lower ratings as usual in the KiGGS (25) and as recommended by Salomon et al. (32). Disagreement between the self- and proxy-reports was defined as a self-rating of general health that was better than the proxy-rating for an individual. Odds ratios (ORs) and 95% CIs were obtained by applying the SAS SURVEY-LOGISTIC procedure.

A multivariable linear regression was applied for the metric outcome of QoL (subscores and total score). The self- and proxy-reports as well as discrepancies between the self- and proxy-reports were analyzed. Disagreement between the self- and proxy-reports was defined as the numeric difference between the self- and proxy-reported KINDL-R scores. To identify differences between the diabetes study and the KiGGS, the adjusted average score differences (β) and SE were estimated using the SAS SURVEYREG procedure.

For each outcome, two models were used for logistic and linear regression analyses: model 1 (M1) included age group, sex, and study as the independent variables, and model 2 (M2) added the variables socioeconomic status, immigration

background, region, caregiver, proxy-informant, weight status, and hospitalization as independent categoric variables. $P < 0.05$, based on two-tailed tests, was considered statistically significant.

RESULTS

Descriptions of the study populations

The characteristics of the participants in the patient and comparison groups are given in Table 1. Additional characteristics of the sample with type 1 diabetes included a mean (SD [range]) manifestation of the disease at the age of 2.7 years (1.1 [0.6–4.9]) and a mean diabetes duration of 12.5 years (1.6 [10.0–16.5]). The mean HbA_{1c} was 8.3% (1.3 [5.6–14.4]). The proportions of patients with $HbA_{1c} \leq 7.5\%$, >7.5–$\leq 9.0\%$, and $>9.0\%$ were 32.5%, 43.2%, and 24.3%, respectively. Continuous subcutaneous insulin infusion (CSII) was used by 48.8% of the patients, multiple daily injection (MDI) therapy (≥ 4 daily injections) was used by

43.3%, and conventional therapy (CT; 1–3 daily injections) by 7.9%.

General health status

"Excellent" general health was reported by 19.8% of the youths with diabetes and 23.0% of KiGGS participants (Table 2). The OR (95% CI) for the self-reported "excellent" general health of the patients versus the comparison group was 0.82 (0.66–1.01; $P = 0.063$) in the minimally adjusted model (M1) and 0.83 (0.66–1.04; $P = 0.101$) in the fully adjusted model (M2).

The proportion of parents with "excellent" ratings of their children's general health was lower in the diabetes study (21.4%) than in the KiGGS (32.5%; Table 2). The OR (95% CI) of the proxy-reports was 0.58 (0.48–0.71; $P < 0.001$) in the M1 and 0.60 (0.48–0.74; $P < 0.001$) in the M2.

Table 3 shows the disagreement between the self- and proxy-reports. The proportion of youths who rated their own health higher than their parents' ratings was higher in the diabetes study than in

Table 1—Description of the two study populations

	Diabetes study* $n = 629$	KiGGS† $n = 6,813$	P
Boys	54.1	51.3	0.188
Age (years)	15.3 (1.7)	14.6 (2.0)	<0.001
11–13	24.0	39.6	
14–17	76.0	60.4	
Socioeconomic status			
Low	17.9	27.4	<0.001
Intermediate	48.2	47.2	
High	33.9	25.3	
Immigrant background	1.8	17.5	<0.001
Region of residence			
West	86.2	81.4	0.003
Family structure			
Biologic parents	79.2	74.6	0.070
Mother and partner/father and partner	9.3	10.6	
Single mother/father	10.4	13.6	
Other‡	1.1	1.3	
Informants of the proxy-reports			
Mothers	71.7	81.0	<0.001
Fathers	6.4	11.1	
Mothers and fathers	20.8	4.7	
Others	1.1	3.2	
BMI			
Underweight	3.3	7.5	<0.001
Normal weight	80.7	74.8	
Overweight (including adiposity)	16.0	17.7	
Hospitalization during last 12 months			
No	72.4	92.4	<0.001
Yes	27.6	7.6	

*Percentages and means (SD). †Weighted percentages and weighted means (SD). ‡Relatives, foster parents, youth institutions.

Table 2—Self- and proxy-reported general health status

General health status*	Self-reports (%)		Proxy-reports (%)	
	Diabetes study	KiGGS	Diabetes study	KiGGS
Excellent	19.8	23.0	21.4	32.5
Good	62.6	62.0	63.2	58.9
Moderate	15.8	14.5	13.8	8.2
Poor/very poor†	1.8	0.6	1.6	0.4

*Information on the general health was not available for 8 self-reports and 4 proxy-reports in the diabetes study and for 1,414 self-reports and 149 proxy-reports in the KiGGS. †Response options were combined.

the KiGGS (17.3% vs. 13.2%). The ORs (95% CI) for higher ratings on the self- than the proxy-report were 1.37 (1.09–1.73; $P = 0.006$) in the M1 and 1.56 (1.21–2.01; $P < 0.001$) in the M2.

Health-related QoL
The KINDL-R total scores for the self- and proxy-reports did not differ significantly between the two study populations, but some differences were observed in the dimensions of the QoL (Table 4). The self-reported QoL in the "family" dimension was significantly decreased among youths with diabetes compared with the KiGGS reports, but the dimensions of "school" and "self-esteem" were rated significantly higher in the diabetic group. According to the M2, patients scored, on average, 2.4 points lower for "family" than their KiGGS peers, 3.4 points higher for "school," and 4.4 points higher for "self-esteem." Children and adolescents with diabetes and the KiGGS peers did not differ with regard to self-reported physical and emotional well-being or on the "friends" dimension.

The parents of the patients reported significantly lower scores in the dimensions of "self-esteem" ($\beta = -1.5$), "emotional well-being" ($\beta = -1.8$), and "friends" ($\beta = -1.9$) but higher scores in the dimension "school" ($\beta = 2.3$) than the parents of the comparison group (M2).

In both samples, the youths and their parents rated some dimensions differently and showed differences in the total score. The mean differences between individual self- and proxy-reports are shown in Table 4. Children and adolescents in both samples rated the dimensions "physical well-being," "self-esteem," "school," and total QoL lower than their parents and the dimensions "emotional well-being," "family," and "friends" higher than their parents. The degree of disagreement between the self- and proxy-reports was significantly different between the two samples for the total score and the dimensions "self-esteem," "family," and "friends" (M2). The disagreement between the self- and proxy-reports in the diabetes study was significantly higher on the dimensions "friends" and smaller on the dimensions "self-esteem," "family," and total QoL score than the disagreement in the KiGGS. The largest difference between the two study populations was found for the disagreement between the self- and proxy-reports on the "self-esteem" dimension ($\beta = 5.1$).

CONCLUSIONS—Compared with the general population, the QoL and general health status were not impaired among youths with early-onset type 1 diabetes.

The main strengths of this study are as follows: 1) the recruitment of a large, well-defined population-based cohort with a

type 1 diabetes onset between the ages of 0 and 4 years during 1993–1999; 2) the ability to analyze self- and proxy-reported QoL in up-to-date, intensively treated patients; and 3) the comparability of the implemented questionnaires with the questionnaires used in the KiGGS. The KiGGS provided reference values for the general population.

The main limitations of the study are that the sample was a selected one and that, because of the conditions of sample selection (anonymous diabetes register, registration of the cases a relatively long time ago), little information on nonparticipating patients was available. Presumably, more motivated patients with better metabolic control and better QoL participated. Compared with similar studies analyzing the QoL of youths with type 1 diabetes, the mean reported HbA_{1c} of our sample (8.3%) was in the reported range (7.7–8.7% [13–19]). Data on average HbA_{1c} from clinical records in the year before participation were available for a subgroup of 442 patients (mean HbA_{1c}, 8.1% [SD 1.3]). The patient group differed significantly from the KiGGS with respect to some potential confounding variables (Table 1). Therefore, to obtain valid results, we considered all of these factors in the analyses. Even so, the comparison of QoL between the diabetic sample and the KiGGS may be biased because the diabetic cohort was presumably not representative. Some findings may be attributed to methodologic differences between the two studies for which we could not adjust (e.g., data collection at home vs. at the study center). Joint completion of parents might have introduced additional variability in the measures from the parents, which may not sufficiently be controlled for in our analysis. There is no information on secular trends in the general population, but we expect that the 3–7 years that separated data collection

Table 3—Disagreement between self- and proxy-reported general health status

General health status		Proxy-reports							
		Diabetes study				KiGGS			
		Excellent	Good	Moderate	Poor/very poor*	Excellent	Good	Moderate	Poor/very poor*
Self-reports	Excellent	9.4	9.7#	0.5#	0.0#	13.6	8.7#	0.6#	0.1#
	Good	11.2	45.2	6.0#	0.5#	16.3	42.3	3.5#	0.1#
	Moderate	1.1	8.1	6.0	0.7#	1.6	8.7	3.7	0.2#
	Poor/very poor*	0.0	0.3	1.0	0.5	0.0	0.2	0.3	0.1

The marginal totals differ from Table 2 because of rounding errors and missing values. Information on the general health was not available for 11 combined self- and proxy-reports in the diabetes study and 1,538 combined self- and proxy-reports in the KiGGS. *Response options were combined. #Cells represent proportions of cases with better self-ratings than proxy-ratings.

Table 4—QoL in 11- to 17-year-old subjects with early-onset type 1 diabetes compared with peers from the KiGGS

QoL	Self-reports				Proxy-reports				Difference between self- and proxy-reports			
	Diabetes study†	KiGGS†	M1*	M2#	Diabetes study†	KiGGS†	M1*	M2#	Diabetes study†	KiGGS†	M1*	M2#
			P	P			P	P			P	P
Physical well-being	69.4	70.6	−0.60	−0.23	72.4	74.1	−1.54	−1.53	−3.1	−3.4	0.79	0.92
	(19.2)	(16.5)	(0.78)	(0.82)	(20.5)	(17.4)	(0.85)	(0.91)	(19.6)	(17.6)	(0.83)	(0.89)
			0.440	0.779			0.071	0.093			0.337	0.301
Emotional well-being	80.0	81.1	−0.77	−0.87	77.5	79.2	−1.71	−1.82	2.5	1.9	0.95	0.76
	(14.4)	(13.1)	(0.61)	(0.63)	(14.6)	(13.2)	(0.62)	(0.66)	(16.1)	(15.2)	(0.69)	(0.74)
			0.204	0.169			0.006	0.006			0.168	0.307
Self-esteem	63.4	58.3	4.41	4.39	66.2	67.3	−1.06	−1.48	−2.9	−9.0	5.38	5.07
	(18.8)	(18.4)	(0.79)	(0.82)	(15.8)	(15.2)	(0.67)	(0.71)	(19.4)	(20.4)	(0.83)	(0.90)
			<0.001	<0.001			0.114	0.037			<0.001	<0.001
Family	78.7	81.9	−2.78	−2.42	74.3	76.4	−1.99	−1.27	4.3	5.5	−0.80	−1.72
	(18.2)	(15.7)	(0.76)	(0.80)	(16.7)	(15.1)	(0.71)	(0.75)	(16.0)	(15.8)	(0.68)	(0.73)
			<0.001	0.002			0.005	0.092			0.240	0.019
Friends	77.6	77.4	0.82	1.10	75.3	77.1	−1.88	−1.94	2.5	0.3	2.95	3.00
	(15.7)	(15.0)	(0.67)	(0.70)	(15.7)	(14.2)	(0.67)	(0.72)	(16.1)	(15.6)	(0.70)	(0.75)
			0.223	0.116			0.005	0.007			<0.001	<0.001
School	69.6	66.1	4.45	3.41	73.4	71.4	3.00	2.30	−3.6	−4.7	1.20	0.73
	(17.8)	(17.2)	(0.75)	(0.77)	(15.2)	(15.9)	(0.65)	(0.70)	(16.4)	(16.9)	(0.71)	(0.76)
			<0.001	<0.001			<0.001	0.001			0.091	0.336
Total score	73.1	72.6	0.94	0.89	73.1	74.2	−0.90	−0.98	−0.1	−1.6	1.81	1.45
	(12.2)	(10.4)	(0.50)	(0.52)	(12.1)	(10.3)	(0.51)	(0.53)	(11.3)	(10.4)	(0.48)	(0.51)
			0.061	0.087			0.075	0.066			<0.001	0.005

In the diabetes study, information on the total QoL was not available for 12 self-reports, 7 proxy-reports, and 18 combined self- and proxy-reports. Information on the six subscores of QoL was not available for up to 19 self-reports, up to 18 proxy-reports, and up to 30 combined self- and proxy-reports of the diabetes study. In the KiGGS, information on the total QoL was not available for 164 self-reports, 290 proxy-reports, and 425 combined self- and proxy-reports. Information on the six subscores of QoL was not available for up to 218 self-reports, up to 497 proxy-reports, and up to 631 combined self- and proxy-reports of the KiGGS. †Unadjusted means and SD. *Average differences (β and SE) between the diabetes study and the KiGGS (reference group) adjusted for age group and sex. #Average differences (β and SE) between the diabetes study and the KiGGS (reference group) adjusted for age group, sex, socioeconomic status, immigration background, region of residence, family structure, proxy-informant (except self-reports), weight status, and hospitalization during last 12 months.

for both groups did not affect our results seriously. A general limitation of QoL analyses is that QoL measurements represent an underlying construct that cannot fully be operationalized by the response to a set of items (8).

The proportion of youths who reported "excellent" general health was comparable in the patient and comparison groups. However, the parents in the patient group reported "excellent" general health less often than the parents in the comparison group. It cannot be excluded that parents of diabetic patients may have tended to rate, for example, "good" instead of "excellent" to indicate that their children have a chronic condition.

Our results do not indicate a general impairment of QoL in intensively treated children and adolescents with early-onset type 1 diabetes compared with their peers in the general population. Neither the patients themselves nor their parents reported significantly reduced KINDL-R total scores. Previous studies have usually observed impaired self-reported and/or parent-reported QoL (13–17,19). Differences between studies might be attributable to different questionnaires used or changes in treatment methods.

A meta-analysis showed fewer differences in well-being between youths with diabetes and their peers in more recent studies; the analysis also found that youths with diabetes experience even better self-esteem than comparison groups. This finding was attributed to improved diabetes treatment (33). Most patients in our study were treated with MDI or CSII. In contrast to our study, insulin therapy with CSII was rarely used in the studies that described therapeutic regimens. The insulin regimens in these studies were two to three injections (94%) and four injections (6%) (15), two to three injections (45%) and four injections (55%) (17), or three to four injections (100%) daily (16). The KINDL-R total score did not differ between CT, MDI, and CSII patients in our study, and adjustment for sex and age group did not alter the results. Individually tailored therapy regimens, together with comprehensive diabetes education that covers medical and psychosocial aspects of diabetes, and the provision of support (e.g., regarding family conflict, decision-making autonomy), are probably important for both patients and parents (3,34).

From a methodologic point of view, a possible explanation for the lack of significant group differences might be that the generic measure KINDL-R (although besides PedsQL most suitable for monitoring QoL in youths with diabetes [29]) has limited sensitivity to reflect the specific effects of the disease and its treatments on QoL (7,9). The nonimpaired QoL observed among youths with long-lasting type 1 diabetes, from a psychologic point of view, may be attributed to the readjustment of goals and ambitions over the years and the adoption of functional coping styles (7,35). Because the analysis was based on a cross-sectional survey, which can only provide a snapshot view of a child's QoL (9), we can only speculate about interactions between personality variables such as individual resilience, disease management, and QoL (4,7).

Children and adolescents generally report fewer adverse effects on QoL than parents (10). However, our results only show this relationship between self- and proxy-reports for the single-question measure and not for the multidimensionally measured QoL. The higher agreement between self- and proxy-reports in the diabetes study compared with the KiGGS may be attributed to the assistance that is provided to children with diabetes by their parents at home. Another explanation may be that the greater need for communication about the disease and its treatments increases the agreement between patients and parents (10).

The most notable difference between the patient group and the reference group was the improved self-reported self-esteem and well-being at school for youths with diabetes. Similar positive associations have rarely been described. Nakamura et al. (19) observed higher scores in the dimension reflecting "strength/diligence/self-esteem" in primary and junior school children than in healthy control subjects. Wagner et al. (17) observed higher scores for the dimensions "school" and "psychological well-being" and attributed these findings to good psychologic adaptation and coping skills resulting from the provision of resources for treatment, educational, and social services. It has been suggested that the management of diabetes with sufficient support enhances strength and self-esteem (19).

In summary, patients with early-onset type 1 diabetes showed normal QoL after 10 or more years of diabetes duration compared with the general population. The finding that even improved QoL is possible in intensively treated children and adolescents with early-onset type 1 diabetes should be encouraging to those engaged in diabetes care.

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