








# Health-related quality of life among adolescents with type 1 diabetes since the second wave of the COVID-19 pandemic in Germany

Juliane Regina Framme <sup>1</sup>, Su-Jong Kim-Dorner <sup>1</sup>, Bettina Heidtmann <sup>2</sup>,  
Thomas Michael Kapellen <sup>3,4</sup>, Karin Lange <sup>1</sup>, Olga Kordonouri <sup>5</sup>,  
Heike Saßmann <sup>1</sup>

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<sup>1</sup>Medical Psychology, Hannover Medical School, Hannover, Germany

<sup>2</sup>Paediatric Endocrinology and Diabetology, Catholic Childrens Hospital Wilhelmstift, Hamburg, Germany

<sup>3</sup>Hospital for Children and Adolescents, University of Leipzig Medical Center, Leipzig, Germany

<sup>4</sup>Department of Paediatrics, MEDIAN Children's Hospital "Am Nicolausholz", Bad Kösen, Germany

<sup>5</sup>Diabetes Center for Children and Adolescents, Auf der Bult Children's Hospital, Hannover, Germany

## Correspondence to

Dr Heike Saßmann;  
sassmann.heike@mh-hannover.de

## ABSTRACT

**Objective** The COVID-19 pandemic had an impact on everyday life and in general, reduced the health-related quality of life (HRQoL) of adolescents. In this study, we assess the HRQoL of adolescents with type 1 diabetes (T1D) in Germany since the second wave of the COVID-19 pandemic by using self-report and parent-proxy reports, to identify risk factors, to compare to peers and to examine the agreement of HRQoL between parents and their children.

**Methods** A total of 445 adolescents (12–18 years) and 413 parents participated in an anonymous cross-sectional survey conducted at three German diabetes centres from January 2021 to June 2022. Inclusion criteria were diabetes duration  $\geq 1$  year and German-speaking. Teen HRQoL was assessed by using self-report and parent-proxy report versions of the KIDSCREEN-10 index.

**Results** The majority of adolescents reported average (75.5%) HRQoL. Approximately 11.3% of teens reported high and 13.2% low HRQoL. Teen's female gender, older age, higher diabetes burden and parental depression symptoms contributed to lower self-reported HRQoL among teens. For parent-proxy reports, increasing diabetes burdens, parental depression symptoms, non-migrant status, high education and ketoacidosis contributed to lower scores on teen HRQoL. The mean scores of the KIDSCREEN-10 index for adolescents did not differ from the German norm. In comparison to healthy peers during the first wave of the pandemic, adolescents in the current study reported higher HRQoL. The overall teen-parent agreement was fair although parents reported significantly lower teen HRQoL than adolescents did.

**Conclusions** HRQoL of most adolescents with T1D during the COVID-19 pandemic was average with parents reporting significantly lower scores. Self-reported and parent-proxy-reported HRQoL and the level of agreement due to different perspectives can provide important information for clinical care and intervention planning.

## INTRODUCTION

The COVID-19 pandemic with its regulations and restrictions has been stressful for most families. Disruption in daily routine occurred through quarantines, contact restrictions,

## WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ The COVID-19 pandemic had a negative impact on the lives of families with increased rates of mental health issues and lower health-related quality of life (HRQoL).

## WHAT THIS STUDY ADDS

⇒ During the middle and towards the end of the COVID-19 pandemic in Germany, adolescents with type 1 diabetes (T1D) rated their HRQoL to be average. Adolescents' diabetes burden and parental depressive symptoms contributed to lower self-report and parent-proxy-reported HRQoL of adolescents with T1D. The teen-parent agreement on HRQoL was fair although parents had a tendency to underestimate their child's HRQoL.

## HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Adolescents' in conjunction with parents' information on HRQoL can provide important information for clinical care and intervention planning in the area of disagreement or low HRQoL.

school closures and limited leisure activities, resulting in a lot of time spent at home with limited contact with the outside.<sup>1</sup> A significant negative impact on well-being and an increase in mental and psychosomatic health problems have been reported in healthy children and adolescents during the pandemic.<sup>2,3</sup> The global health-related quality of life (HRQoL) of children and adolescents dropped significantly and did not recover to prepandemic levels as of October 2022.<sup>4</sup>

The negative impact of the pandemic on well-being was also found among children with type 1 diabetes (T1D) and their parents.<sup>5</sup> Parents of children with T1D have had a higher probability of a positive screening for mental health disorders and experienced significantly higher pandemic-related

emotional burdens compared with parents with healthy children.<sup>6</sup> Adolescents with diabetes are also at a greater risk of experiencing mental health disorders in general<sup>7</sup> and this was linked to reduced HRQoL.<sup>8</sup> The pandemic may have been particularly challenging for this vulnerable group as it was an additional source of concern and distress. Interestingly, regarding the impact of the pandemic on glycaemic control, no relevant changes were found for children in Germany.<sup>9</sup> Some found improvement in glycaemic control during the COVID-19 lockdown for adults.<sup>10</sup> Despite the potential impact of the COVID-19 pandemic on well-being, to our knowledge, there has been no study assessing HRQoL in adolescents with T1D in Germany during the pandemic.

HRQoL in children with diabetes can be assessed by using disease-specific or global HRQoL measures. While former types can address HRQoL dimensions specific to a given disease,<sup>7</sup> data comparisons with those of the general population are limited. HRQoL can be examined through self-report and/or via proxy report depending on the age of the child and their ability to report accurately. The self-reports and proxy reports provide the possibility to examine the differences and agreement, which can be indicative of another dimension such as family functioning. For instance, parents rate their children's HRQoL to be significantly worse than the children themselves do during a crisis<sup>11</sup> and when their child has chronic health conditions.<sup>12–15</sup> However, others have found an overestimation of HRQoL by parents of adolescents with T1D.<sup>16</sup> The informant disagreements between parents and children, regardless of the direction, were often linked to the mental health status of parents.<sup>16,17</sup> Since the parents are still involved in health decisions for most adolescents, parent-proxy reports and the informant agreement are equally important to examine.

Therefore, in the current investigation, using the self-report and parent-proxy report versions of the global KIDSCREEN-10 index,<sup>18</sup> we aimed (1) to assess HRQoL of adolescents with T1D during the COVID-19 pandemic in Germany; (2) to identify contributing factors of HRQoL during the COVID-19 pandemic; (3) to compare our data to other published study results from before and during COVID-19 and (4) to examine agreement between the teens and parents reports. We expected a lower HRQoL among teens with T1D compared with norms and healthy peers during the COVID-19 pandemic, especially for those with high diabetes distress and insufficient glycaemic control.

## MATERIALS AND METHODS

### Participants and procedures

Participants were adolescents between 12 and 18 years old with T1D and their parents visiting one of the three paediatric diabetes centres in Germany during a routine check-up. Further inclusion criteria were German-speaking and diabetes duration of at least 1 year to reduce the potential impact on well-being due to new diagnosis

and uncertainty of disease progression. Data collection took place from January 2021 to June 2022. This time frame includes the period from the second lockdown to the ease of most federal regulations regarding COVID-19. All participants were informed of the purposes of the study and provided verbal consent. The questionnaire was self-completed and left in a collection box in the waiting area. The questionnaire was completely anonymous and dyads were identified based on their matching questionnaire IDs. Although family pairs were recruited, incomplete data from one party was not an exclusion criterion for the other.

### Measures

The study questionnaire included: (1) sociodemographic data, (2) clinical information and (3) psychometric instruments: KIDSCREEN-10 index (self/parent-proxy version), the Problem Areas in Diabetes-Teen (PAID-T) and Parent-Problem Areas in Diabetes-Teen (P-PAID-T), and the Patient Health Questionnaire-9 item (PHQ-9) for parents.

### Demographic and clinical data

Gender, age, living situation, country of birth and education were collected. Clinical measures included age at diagnosis, diabetes duration, current use of continuous subcutaneous insulin infusion (CSII) and continuous glucose monitoring (CGM), the prevalence of severe hypoglycaemia and diabetic ketoacidosis (DKA)<sup>19</sup> in the past 12 months ('yes' or 'no') and glycated hemoglobin (HbA1c). Current HbA1c levels were entered into the questionnaire by the participant during the medical examination. Local HbA1c values were mathematically standardised to the Diabetes Control and Complications Trial reference range (4.05%–6.05%) to adjust for different laboratory methods by using the multiple of the mean transformation method.<sup>20</sup>

### Psychometric measures

The KIDSCREEN-10 index for self and proxy is the shortest version of KIDSCREEN instruments.<sup>18,21</sup> It provides a singular index of global HRQoL covering physical, psychological and social facets of HRQoL in healthy and chronically ill children and adolescents from 8 to 18 years. Ten items are rated on a 5-point Likert scale ranging from 'never' (1) to 'always' (5) with higher values indicating higher HRQoL. The period refers to last week. The KIDSCREEN-10 index has good to excellent internal consistency values (Cronbach's  $\alpha$  for self and proxy version=0.82 and 0.78, respectively), and test-retest reliability, intraclass correlation coefficient (ICC), was 0.70 and 0.67, respectively.<sup>18</sup> Reference norms as T-Scores for German teens are available.<sup>21</sup>

The 14-item and 15-item PAID-T/P-PAID-T measures diabetes-specific distress in adolescents (12–18 years) and parents, respectively.<sup>22</sup> Respondents rate how much each item bothered them over the past month using a 6-point Likert scale from 'not a problem' (1) to 'serious problem'

(6) with higher scores indicating higher distress. The summed total PAID-T score can range from 14 to 84 and the total P-PAID-T from 15 to 90. Both questionnaires demonstrated excellent reliability with Cronbach's  $\alpha=0.91-0.93$  for teens and  $0.93-0.94$  for parents.<sup>22 23</sup>

The PHQ-9 was used to assess parents' depressive symptoms. Each of the nine items corresponds to the Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV) criteria for a diagnosis of major depressive disorder.<sup>24</sup> Each item is rated on a 4-point Likert scale of 'not at all' (0) to 'nearly every day' (3). The summed total score ranges from 0 to 27 with higher scores indicating a higher probability of depression. Parents were categorised based on their depressive symptoms: no symptoms (0-4), mild (5-9) and moderate to severe depressive symptoms ( $\geq 10$ ).<sup>25</sup> The PHQ-9 showed  $\alpha=0.89$  and test-retest reliability of  $r=0.84$ .<sup>25</sup>

## Statistical methods and data analysis

### Data management

The T-values based on Rasch person parameters were calculated following the KIDSCREEN guidelines.<sup>21</sup> The T-scores were tolerant for  $\leq 1$  missing entry for teens but no missing was allowed for parents' T-scores. The T-scores were used to identify three groups with differing levels of HRQoL:  $<40$  as low,  $40-60$  average and  $>60$  as high HRQoL. For single-item analysis for KIDSCREEN and other analyses, all available data were analysed using pairwise deletion to maximise the data use. One missing in the PAID-T, P-PAID-T and PHQ-9 was imputed with the participant's own mean using the rest of the completed items to obtain total scores.

### Comparison data

The T-scores from this study were compared with the results of four German studies that used the KIDSCREEN-10 index self-report and parent-proxy report versions. Two studies were conducted before the outbreak of COVID-19: national norm data for German adolescents aged between 12 and 18 years published with the KIDSCREEN manual<sup>21</sup> and a study conducted in 2012-2016 including 1058 German teens aged between 11 and 17 years living with T1D.<sup>16</sup> The latter sample of adolescents with T1D comprised of 49% girls with a mean ( $\pm$ SD) age of  $14.3\pm 1.5$  years. The mean HbA1c was  $66.2\pm 15.3$  mmol/mol and 79% of the children were living with their biological parents. Two further studies conducted during the COVID-19 pandemic were included. The German population-based COroNa und PSYche (COPSY) study examined HRQoL of 1040 healthy adolescents (51.1% girls) between 11 and 17 years of age in May-June 2020.<sup>11</sup> The mean age of the adolescents was  $14.33\pm 1.86$  years and parents was  $46.28\pm 6.74$ . Approximately 15.5% of the participants had a migration background and 53.9% of the parents worked full time. The other study is the German region Siegen-Wittgenstein study from July to September of 2021 including 908 parents and 1412 healthy teenagers (49.2% girls) aged 12-17 years ( $14.3\pm 1.64$ ).<sup>26</sup> The mean age of

parents was  $46.0\pm 5.98$  years and 72% of the participating parents were mothers.

### Data analyses

Data were analysed by using IBM SPSS Statistics V.28 for Windows (IBM). The statistical significance level was set at  $p<0.05$  (two tailed). Group differences were examined by using independent t-tests or analysis of variance if more than two groups were compared. Cut-off values were used to compare groups for HbA1c and age. Following the International Society for Pediatric and Adolescent Diabetes (ISPAD) guidelines, the target HbA1c level was defined as  $<7.0\%$  (53 mmol/mol).<sup>27</sup> Age groups were categorised from 12 to 13, 14 to 15 and  $\geq 16$  years according to the German legal system with increasing permissions, which reflect the adolescent's level of maturity and independence. For example, limited contractual capability starts at the age of 14 and compulsory full-time schooling normally ends at the age of 16.

Two separate linear regression analyses were performed to examine the influence of demographic, clinical and psychological measures on self-reported and parent-proxy-reported HRQoL. Independent variables included demographic variables (teen's and parent's age and gender, parental migrant status (born in Germany vs abroad), and parental education (completion of 12 years of school, yes vs no)), clinical (CSII (yes vs no), CGM (yes vs no), severe hypoglycaemia (yes vs no), DKA (yes vs no), diabetes duration, and HbA1c%), and psychological measures (PAID-T/P-PAID-T and PHQ-9).

For teen-parent dyads, ICCs were calculated to assess informant agreement<sup>28</sup> on the KIDSCREEN-10 index. Furthermore, the teen's total score subtracted by the parent's score was used to generate three groups indicating different levels of informant agreement following the 'half a SD' threshold<sup>14 29</sup>: in agreement, parent overestimation ( $P>C$ ) and parent underestimation ( $C>P$ ) groups. The raw summed total scores were used for these evaluations instead of the already adjusted Rasch T-scores. The teen-parent agreement was examined as a function of gender, age and depressive symptoms of parents.

### Patient and public involvement

Patients or the public were not involved in the design, or conduct, or reporting, or dissemination plans of our research.

## RESULT

A total of 464 families (527 eligible families: 88% participation rate) agreed to participate in the study. Fourteen (3.1%) teens and 38 (8.3%) parents did not return the questionnaire. Five further family data and eight non-parent proxy data were excluded following the exclusion criteria. The mean age of the teens was  $14.66\pm 1.79$  years and 42.8% were female. The mean diabetes duration was  $6.59\pm 4.04$  years. The mean HbA1c was  $7.76\pm 1.15\%$  ( $61.32\pm 12.56$  mmol/mol). The metabolic target of HbA1c  $<7.0\%$  (53 mmol/mol) was reached by 23.1% of

**Table 1** Sociodemographic, clinical and psychological characteristics

Adolescents characteristics, n=445	M (SD) or n (%)
Age, year	14.66 (1.79)
Gender, female	185 (42.8%)
Age at diagnosis, years	8.10 (3.88)
Diabetes duration, years	6.59 (4.04)
HbA1c, % and mmol/mol	7.76 (1.15) and 61.32 (12.56)
<7.0% (=53mmol/mol)	99 (23.1%)
7.0%–9.0% (=53–75 mmol/mol)	285 (66.6%)
>9.0% (=75 mmol/mol)	44 (10.3%)
Living situation	
Both parents	348 (77.0%)
Mother	83 (18.4 %)
Father	12 (2.7 %)
Other	9 (2.0%)
School	
Upper secondary school	199 (45.7%)
Comprehensive secondary school	103 (23.7 %)
Intermediate secondary school	53 (12.2 %)
Lower secondary school	24 (5.5 %)
Other	56 (12.8%)
Current use of diabetes technology	
CSII	264 (57.5 %)
CGM	356 (77.6%)
Severe hypoglycaemia in the past year, yes	54 (12.0%)
Ketoacidosis in the past year, yes	108 (23.5%)
Psychological questionnaire	
PAID-T	33.98 (13.79)
Parents characteristics, n=413	
Parent relationship to adolescent, mother	306 (75.9 %)
Age	46.81 (6.05)
Birthplace, Germany	334 (83.3%)
Education, completion of 12 or more years	217 (54.0%)
Employment, full time	167 (42.0%)
Psychological questionnaire	
PHQ-9	5.82 (4.53)
P-PAID-T	45.97 (15.76)

The % is calculated excluding missings.  
CGM, continuous glucose monitoring; CSII, continuous subcutaneous insulin infusion; HbA1c, glycated hemoglobin; PAID-T, Problem Areas in Diabetes-Teen; PHQ-9, Patient Health Questionnaire-9; P-PAID-T, Parent-Problem Areas in Diabetes-Teen

the teens. The average age of parents was 46.81±6.05 years and 75.9% were mothers. Further sample characteristics are presented in [table 1](#).

### Self-reported and parent-reported HRQoL measured by KIDSCREEN-10 index

Of the total of 445 teens, 16 were missing one item and 12 were missing more than one. Of the 413 parents, 14 parents were missing one item and four were missing more than one. Data were missing completely at random (MCAR) for both teens and parents: Little's MCAR test  $\chi^2$  (84, N=445)=73.61,  $p=0.78$  and  $\chi^2$  (87, N=413)=108.56,  $p=0.06$ , respectively. Following the KIDSCREEN guideline for generating Rasch T-scores, 433 self-reported and 395 proxy-reported T-scores were available. The mean T-score for the self-report was 50.33±9.97 and the proxy report was 47.85±10.82,  $p<0.001$ . According to the self-report, 327 (75.5%) teenagers had an average, 49 (11.3%) high and 57 (13.2%) low HRQoL. In comparison, 275 (69.6%) of parents reported an average HRQoL for their teen, 38 (9.6%) high and 82 (20.8%) low HRQoL. See [table 2](#) for self-reported and parent-reported HRQoL.

The three age groups reported significantly different levels of HRQoL with the 16–18 years age group reporting the lowest scores ( $p=0.012$ ). Girls reported significantly lower HRQoL than boys ( $p<0.001$ ). Unlike the teen's report, the proxy report on HRQoL did not differ as a function of teens' age and gender. No significant relations were found between both versions of the KIDSCREEN-10 index and parental gender ([table 2](#)) or age (self-report:  $r=-0.034$  and proxy report:  $r=0.083$ ). Both teens and parents reported significantly higher HRQoL in the teens who achieved the target level of glycaemic control. Parents of children with severe acute metabolic complications reported significantly lower HRQoL.

According to the parents' report on PHQ-9, 191 (47.6%) parents had no depressive symptoms, 131 (32.7%) had mild, and 79 (19.7%) had moderate to severe depressive symptoms. Both self-reported and parent-proxy-reported HRQoL were significantly lower when parents had depressive symptoms (both significant at  $p<0.001$ ). For self-report, teens with parents with moderate to severe depressive symptoms reported significantly lower HRQoL in comparison to no-symptom parents; for proxy report, both mild and moderate to severe symptom groups of parents reported significantly worse HRQoL in their children compared with no-symptoms group (both significant at  $p<0.001$ ).

### Predictors of HRQoL

Regression analysis revealed that female gender, increasing age of the teenager and teen-reported diabetes burden contributed lower scores on self-reported HRQoL. Parental depression was the only variable associated with the parent's report that predicted low HRQoL in the teen's self-report. The risk factors for the parents' report of teen HRQoL were DKA in the last year, higher diabetes burdens reported by the teens and parents, increasing depressive symptoms, higher education and being born in Germany (see [table 3](#)).

**Table 2** Mean KIDSCREEN-10 index T-scores of self-report and parent-proxy report

	Self-report, n=433		Parent-proxy report, n=395	
	Mean (SD)	P value*	Mean (SD)	P value*
All	50.33 (9.97)		47.85 (10.82)	
Age		0.012		0.800
12–13 years	51.71 (10.56)	0.0150†	47.79 (11.35)	
14–15 years	51.05 (9.72)	0.075†	47.47 (9.32)	
16–18 years	48.46 (9.41)		48.36 (11.74)	
Gender		<0.001		0.255
Female	47.73 (8.93)		47.13 (10.14)	
Male	52.41 (10.29)		48.42 (11.24)	
Living arrangement		0.784		0.810
With both parents	50.40 (10.13)		47.81 (10.86)	
Other	50.09 (9.47)		48.12 (10.55)	
Glycaemic control		0.043		0.024
HbA1c<7.0%(53mmol/mol)	52.15 (9.71)		50.05 (9.58)	
HbA1c≥7.0%(53mmol/mol)	49.75 (10.06)		47.10 (10.93)	
Severe hypoglycaemia, past 12 months		0.740		0.048
Yes	49.88 (12.71)		44.89 (9.37)	
No	50.50 (9.57)		48.30 (10.98)	
Ketoacidosis, past 12 months		0.069		<0.001
Yes	48.80 (10.30)		43.26 (9.65)	
No	50.86 (9.85)		49.19 (10.82)	
CSII		0.595		0.106
Yes	50.54 (10.56)		47.10 (10.51)	
No	50.03 (9.12)		48.89 (11.20)	
CGM		0.376		0.545
Yes	50.55 (10.10)		47.68 (10.44)	
No	49.52 (9.47)		48.51 (12.30)	
Relationship to the child		0.119		0.718
Mother	50.15 (9.94)		47.73 (11.01)	
Father	52.02 (10.27)		48.20 (10.41)	
Parental education		0.376		0.054
≥12 years	50.18 (10.51)		49.01 (11.03)	
<12 years	51.10 (9.48)		46.87 (10.66)	
Parents PHQ-9		<0.001		<0.001
No depressive symptoms (<5)	52.34 (10.13)		51.83 (10.26)	
Mild symptoms (5–9)	50.18 (9.44)		44.76 (10.40)	<0.001‡
Moderate to severe symptoms (≥10)	47.36 (9.64)	<0.001‡	43.25 (8.36)	<0.001‡

\*P value based on Student's t-test or ANOVA for more than two group comparisons.

†P value based on the Bonferroni comparisons to 16–18 years old group.

‡Comparisons to no depressive symptoms group.

ANOVA, analysis of variance ; CGM, continuous glucose monitoring; CSII, continuous subcutaneous insulin infusion; HbA1c, glycated hemoglobin; PHQ-9, Patient Health Questionnaire-9 .

## Comparison

### Prepandemic

The mean T-Score of German adolescents norm sample before the COVID-19 pandemic (12–18 years) was 50.14±8.41 for self-report and 50.88±9.07 for proxy-report.<sup>21</sup> The self-reported means did not

differ significantly between the prepandemic and the present study adolescent samples, but our sample of parents reported significantly lower teen HRQoL than the parents from the prepandemic study ( $p<0.001$ ). In comparison to the German data of adolescents with T1D before the pandemic (self-report=49.2 ±10.05 and

**Table 3** Contributing factors on self-reported and parent-proxy-reported KIDSCREEN-10 index based on linear regression analyses

	B (SE)	b	95% CI	P value
KIDSCREEN self-report				
PAID-T	-0.403 (0.033)	-0.539	-0.468, -0.338	< 0.001
Female	-3.619 (0.878)	-0.179	-5.347, -1.891	< 0.001
Age	-0.502 (0.248)	-0.087	-0.989, -0.014	0.044
Parental PHQ-9	-0.198 (0.100)	-0.087	-0.394, -0.002	0.048
KIDSCREEN parent-proxy report				
P-PAID-T	-0.132 (0.044)	-0.193	-0.219, -0.045	0.003
PAID-T	-0.192 (0.044)	-0.242	-0.276, -0.108	< 0.001
Parental PHQ-9	-0.532 (0.135)	-0.224	-0.798, -0.267	< 0.001
Parental education $\geq 12$ years	-2.973 (0.976)	-0.140	-4.893, -1.053	0.003
DKA, yes	-3.869 (1.239)	-0.150	-6.306, -1.431	0.002
Parent not born in Germany	3.051 (1.324)	0.107	0.446, 5.656	0.022

Independent variables include adolescent's age, gender, CSII, CGM, hypoglycaemia, ketoacidosis, diabetes duration, HbA1c%, PAID-T; and parent's gender, age, education, immigrant background, P-PAID-T and PHQ-9.

CGM, continuous glucose monitoring; CSII, continuous subcutaneous insulin infusion; DKA, diabetic ketoacidosis; HbA1c, glycated hemoglobin; PAID-T, Problem Areas in Diabetes-Teen; PHQ-9, Patient Health Questionnaire-9; P-PAID-T, Parent-Problem Areas in Diabetes-Teen.

parent-report=52.6  $\pm$ 11.98),<sup>16</sup> our teen sample reported significantly higher HRQoL ( $p=0.019$ ) than adolescents pre-pandemic, but our parent sample reported significantly lower HRQoL ( $p<0.001$ ) than parents of adolescents pre-pandemic.

#### During COVID-19 pandemic

Comparisons to the German COPSYP study data of a representative sample of adolescents during the first wave of the COVID-19 pandemic revealed that sample means in the present study were significantly higher than their respective COPSYP teen (45.38) and parent reported means

(42.36) (both comparisons significant at  $p<0.001$ ).<sup>11</sup> Compared with another group of healthy adolescents from Siegen-Wittgenstein after the third wave of COVID-19, both self-reported and proxy-reported HRQoL in the present study were significantly lower than their respective teen's and parent's reports (teens: 53.7 $\pm$ 11.23 and parents: 51.8 $\pm$ 12.84), both significant at  $p<0.001$ .<sup>26</sup>

#### Teen-parent agreement

The mean and SD for each item and the ICC for dyad recruits are presented in table 4. Poor agreement was found for two items, 'time for oneself' (agreement: 41.0%,

**Table 4** The KIDSCREEN-10 index data for each item and teen-parent agreement

Item description	Teens	Parents	t-test	Teen-parent agreement	
	Mean (SD)	Mean (SD)	P value	ICC*	95% CI
1: Felt fit and well	3.68 (1.07)	3.69 (0.93)	0.947	0.551	0.453, 0.632
2: Felt full of energy	3.52 (0.98)	3.52 (0.90)	0.940	0.643	0.565, 0.707
3: Felt sad†	3.88 (1.05)	3.67 (0.93)	0.002	0.576	0.480, 0.654
4: Felt lonely†	4.26 (0.97)	4.00 (0.99)	<0.001	0.455	0.334, 0.555
5: Had enough time for self	4.05 (0.89)	4.24 (0.66)	<0.001	0.303	0.153, 0.428
6: Did things in free time	3.96 (1.01)	4.07 (0.90)	0.102	0.439	0.315, 0.540
7: Feel treated fairly by parents	4.57 (0.68)	3.89 (0.87)	<0.001	0.327	0.041, 0.516
8: Had fun with friends	4.09 (1.02)	3.81 (0.99)	<0.001	0.537	0.429, 0.623
9: Got on well at school	3.89 (1.04)	3.91 (0.94)	0.795	0.502	0.391, 0.593
10: Pay attention	3.95 (0.87)	3.85 (0.86)	0.088	0.532	0.428, 0.617

According to Cicchetti's guidelines, ICC<0.4 is classified as poor, 0.40–0.59 as fair, 0.60–0.74 as good and 0.75–1.00 as excellent reliability.

\*ICC estimates were calculated with a two-way mixed effects model and absolute agreement of the teen-parent dyads.

†Reverse scored.

ICC, intraclass correlation coefficient.

P>C: 36.1%, C>P: 22.9%) and 'feel treated fairly' (agreement: 36.8%, P>C: 6.5 %, C>P: 56.7%). All other items showed fair agreement except for one item ('felt full of energy') with good agreement. Using the 'half a SD' criterion for the total summed scores, 159 (42.6%) dyads were classified as in good agreement. Overestimation by parents was seen in 77 (20.6%) dyads and underestimation in 137 (36.7%) dyads. Of the teens who indicated their HRQoL to be low (n=45), 28 (62.2%) parents also reported low HRQoL in their teens, but 17 (31.4%) reported average HRQoL in their teens. Girls' parents overestimated more often than boy's parents ( $p<0.001$ ) but the agreement did not differ based on the teen's age. Parents with any depressive symptoms (PHQ-9 $\geq$ 5) tended to underestimate their teens' HRQoL ( $p<0.001$ ). HbA1c did not differ by the informant agreement on HRQoL ( $p=0.174$ ).

## DISCUSSION

The majority of adolescents with T1D rated their general HRQoL as average or even high, and only 13.2% reported low HRQoL. As seen in previous studies,<sup>30 31</sup> we found lower HRQoL in girls compared with boys and in older teens compared with younger teens. Possible reasons for gender differences in HRQoL include hormonal influences, differences in character and specific coping mechanisms, which may be linked to reduced psychological well-being in adolescent girls.<sup>32</sup> Lower HRQoL in older adolescents could be explained by cumulative stress associated with increasing societal demands in addition to numerous biological changes.<sup>32</sup> Adolescents with T1D become increasingly responsible for their diabetes management during this developmental phase, which can add another major source of stress.<sup>7</sup> However, gender and age differences in self-reported HRQoL have not been consistently reported in previous studies,<sup>2 14 16</sup> and according to our parent-proxy report, no difference in HRQoL was found as a function of age or gender of adolescents. To our knowledge, this was the first study to assess HRQoL among adolescents with T1D by using self-report and parent-proxy reports during the COVID-19 pandemic in Germany.

Parents assessed HRQoL of their teens to be significantly lower than the teens themselves did. Our finding is corroborated by other studies<sup>12 13 33</sup> demonstrating that parents of children with health conditions tend to underestimate their children's HRQoL. In our study, parents' estimation of HRQoL was lower than that of the parents of healthy peers' prepandemic level although children's self-reported did not differ.<sup>21</sup> This may be because parents compare the situation of their child with one of their healthy peers, and this leads to underestimating HRQoL in their chronically ill child.<sup>14</sup>

In the present study, both teens and parents reported lower HRQoL for teens with HbA1c above the target range. This is aligned with findings from other studies.<sup>15 30 34</sup> As puberty, in particular, is a time in which

poorer glycaemic control is more common,<sup>35</sup> early detection of deteriorating HRQoL is recommended. Therefore, it is important to include psychological assessment in routine clinical diabetes care.<sup>7</sup> Diabetes Distress and depressive symptoms in parents were associated with adolescents' and parents' estimation of HRQoL in teens. Previous studies have demonstrated that parental mental health status is related to the reduced proxy estimation of child HRQoL.<sup>2 16 17</sup> The presence of moderate to severe depressive symptoms assessed in PHQ-9 was high in our sample (19.7%). Considering this, support services should be offered to parents of children with diabetes to prevent these negative outcomes.<sup>7</sup> This is especially important in extreme situations like the COVID-19 pandemic where greater stress for parents of children with T1D was found.<sup>36</sup>

Interestingly, being born in Germany was a predictor for worse proxy-reported child HRQoL. This result might be explained by framing processes or cultural differences. High parental education was also associated with lower proxy-reported HRQoL. Educated parents may have a better understanding of health issues and risks, which can lead them to evaluate child HRQoL more critically. A study of children after liver transplantation found similar results that seem to indicate that better parental knowledge about the disease is associated with worse perceptions of the child's well-being.<sup>37</sup>

Another notable finding was the frequent report of severe hypoglycaemia and hyperglycaemia (DKA) by the adolescents. Among clinically and demographically comparable German teens with T1D, 5.6% had more than one episode of DKA in a 1-year period.<sup>38</sup> This significant difference in the DKA rate is most likely because our report relied on self-report rather than following strict clinical criteria for DKA. Teens' reports were subject to their own interpretation of the symptoms. Despite self-reported events of these episodes in our study being very different from the national data, DKA was a risk factor for the parent proxy reported but not self-reported HRQoL. Whether the experience of these symptoms in teens was communicated to parents is unclear. However, parents seem to incorporate clinical outcomes into assessing their child's quality of life whereas adolescents themselves did not. Our finding warrant further investigations on the perceived acute complications in general well-being by the proxy reports.

In contrast to our hypothesis, HRQoL of adolescents in this study did not differ from the German norm sample before the pandemic. Compared with healthy peers during the first wave of the COVID-19 pandemic in the COPS study, adolescents in our study showed significantly higher levels of HRQoL. This result could be indicative of successful support and guidance through paediatric diabetes teams, which often included telemedical care. Moreover, adolescents with T1D may have been more successful in self-organisation and self-regulation during the pandemic by establishing daily routines, which is part of diabetes management training. An Italian study

has also demonstrated that most children and adolescents with T1D developed high levels of resilience and excellent coping skills during the initial wave of the COVID-19 pandemic.<sup>39</sup> Average to high HRQoL in our sample could be an adaptation to the new normalcy and establishment of coping mechanisms to deal with restricted daily life.

As the COPSYS data were collected at the beginning of the pandemic in 2020 the lifestyle change was drastic.<sup>11</sup> Possibilities such as vaccination enabled the return to a more normal daily living,<sup>26</sup> which is probably the reason why HRQoL increased again over the course of the pandemic. This was evidenced in the study of healthy adolescents from the Siegen-Wittgenstein region on the verge of vaccination after the third wave of COVID-19 demonstrating significantly higher HRQoL than in COPSYS samples.<sup>26</sup> However, in the study of healthy adolescents from Siegen-Wittgenstein and our study of adolescents with diabetes, parents underestimated the HRQoL of teens, indicating that the pandemic is viewed as a critical situation in which parents seem to rate child HRQoL lower.<sup>11</sup> An increased incidence of mental health problems during the pandemic in parents may explain the underestimation of their teen's HRQoL. The pandemic may have been a trigger for the manifestation of latent anxiety and depressive symptoms in parents.<sup>6</sup> Parents with depressive symptoms perhaps perceive the complexity of diabetes and the challenges of treatment as more negative and stressful, yet lack the necessary coping skills.<sup>6</sup> Thus, mental health problems seem to influence parents' views on their child's HRQoL.<sup>17</sup>

With regard to the informant agreement on each item, two items had poor teen-parent agreement. The item with the worst agreement was 'time for myself' with parents overestimating this item. This disagreement could be an indication of a higher need for young people to have free time. The other item of low agreement was the perception of fair treatment by the parents with parents underestimating this item. This could reflect parents' concern about being an unfair parent and evaluating their own behaviour harshly although this item had the highest score according to the teens. These items could be important topics in consulting sessions, especially when HRQoL is low. Considering the moderate level of teen-parent agreement on the KIDSCREEN-10 index in general, both versions are recommended to assess teen HRQoL in clinical care. The child-parent disagreement should not be seen as failures in estimation<sup>14 17</sup> but instead a different understanding and experience of the situation. This further emphasises the necessity of gathering information from multiple sources, particularly as the management of a chronic disease like T1D in a child affects the whole family.<sup>40 41</sup>

Our study has several limitations. Due to the cross-sectional design, we were not able to compare HRQoL over time. Also, we did not have a control group of healthy adolescents in the same period and the same region. As the COVID-19 restrictions differed on the exact time period and region in Germany, direct comparisons were

limited. In addition, the mean glycated haemoglobin values covering our entire study period from multiple visits would have been ideal, but due to the anonymous nature of the study, a review of the medical record was not possible. Similarly, we could not check or confirm the accuracy of clinical data.

## CONCLUSIONS

Overall HRQoL during the COVID-19 pandemic was average among adolescents with T1D. Self-reported and proxy-reported HRQoL was higher in this study compared with healthy adolescents during the first wave. Compared with adolescents with T1D before the COVID-19 pandemic, self-reported HRQoL was higher, while parent-proxy report was lower, emphasising the impact of the COVID-19 pandemic on parents' perspective. In both self-reported and proxy-reported KIDSCREEN-10 index, diabetes distress and parents' depressive symptoms predicted lower teen HRQoL. Regular monitoring of HRQoL can help to identify areas of concern and allow for timely interventions to improve the overall well-being of adolescents with T1D and their families. Self-report and proxy-report versions can deliver additional information about different perspectives. Self-reported HRQoL in adolescents with T1D, together with their parent's view, can provide important information for clinical care and intervention planning.

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## ORCID iDs

Juliane Regina Framme <http://orcid.org/0000-0003-4130-4644>

Su-Jong Kim-Dorner <http://orcid.org/0000-0003-3927-7333>

Bettina Heidtmann <http://orcid.org/0000-0001-6343-9000>

Thomas Michael Kapellen <http://orcid.org/0000-0002-0632-4044>

Karin Lange <http://orcid.org/0000-0002-3636-2025>



Olga Kordonouri <http://orcid.org/0000-0001-9563-3537>  
 Heike Saßmann <http://orcid.org/0000-0003-4557-8597>

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