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Health-Related Quality of Life in Children and Youth with Type 1 Diabetes Living in Eastern and Southern Highlands, Tanzania

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ABSTRACT

Introduction: Patients with type 1 diabetes mellitus (T1DM) face many challenges. Little information exists on Quality of Life (QoL) in children and adolescents with T1DM in Tanzania. The objectives of our study were to: 1. Assess the health-related QoL (HR-QoL) in youth with T1DM and compare it to the perception by their parents; 2. Compare the overall QoL of children and adolescents with and without T1DM. **Methods:** This cross-sectional study was performed in a convenience sample of children and adolescents with T1DM living in rural Tanzania. HR-QoL was assessed in patients with T1DM and in their parents using translated PedsQL™ questionnaires. The general QoL in patients with diabetes and in controls of the same sex and age was compared using the Kid-KINDL® and the Kiddo-KINDL® questionnaires. **Findings:** Twenty-one patients with T1DM aged 7-13 and 14-17 years were recruited. Overall, patients with T1DM HR-QOL complained "often" or "almost always" about their worries of going "low" (40%) or "high" (33%) and about whether the medical treatment was working (33%). There was no statistical difference in the perception of issues related to diabetes between children/adolescents and their parents. Compared to control children and adolescents, youth with T1DM reported a statistically significant lower QoL in most domains: physical health, overall feeling in general and about themselves, relationships with family and friends, and how they felt about school ($p < 0.05$). Our results will help Tanzanian health professionals and families to advocate for more resources towards better health education, community programs that address stigma and bias associated with T1DM, greater involvement of the schools and better access to care. **Conclusion:** T1DM equally affects the QoL of children and adolescents and of their parents. In addition, patients with T1DM have a lower QoL than children and adolescents without T1DM.

Key words: Quality of life, Tanzania, Type 1 diabetes, children and adolescents

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INTRODUCTION

Thanks in large part to improved diagnosis, the prevalence of Type 1 diabetes (T1DM) is increasing in sub-Saharan Africa and T1DM is now becoming an important public health issue [1-3]. Recent data from Tanzania estimated the annual number of incident cases of T1D in children and adolescents aged 0-14 years at 479 (incidence of 1.8

new cases per 100,000 per year) and aged 0-19 years at 1189 (incidence of 4.0 new cases per 100,000/year) [4]. In addition, the characteristics, and outcomes of T1DM in sub-Saharan Africa are influenced by their interaction with infectious diseases [5-6]. Studies in pediatric sub-populations in general and in Tanzania in particular, show that glycemic control is poor and that HbA1c is higher than recommended compared to what is observed in high-income countries despite recent improvements in access to insulin and education. The causes for this suboptimal outcome are multifactorial and include poor adherence to insulin treatment and to dietary measures as well as limited access to blood glucose monitoring [7-10].

In Tanzania, until the age of 18, children and adolescents are considered as dependents and are supported by the National Health Insurance Fund (NHIF) through their family/caretaker. Thanks to services and support offered by Changing Diabetes in Children (CDiC) and by the International Diabetes Federation (IDF) (through the Life for a Child [LFAC] program), diabetes care has been free for children and youth for the last 14 years. Thanks to these programs, patients receive free insulin until the age of 18 years (CDiC) or 24 years (LFAC). One of the expectations of these programs is that the Government progressively takes over the care of children and adolescents with diabetes. This is presently taking place by the increasing distribution of essential drugs to eligible public facilities.

The situation of young patients after they reach 24 or 18 years of age and stop qualifying for the CDiC and IDF LFAC programs is difficult [11]. Children and youth are poorly equipped to make the right decisions around their personal health care unless their family supports them. Specifically, except for the few patients who are enrolled in college, access to government-subsidized care is an issue in young adults as few patients have a job (National Health Insurance Fund (NHIF), Tanzania, www.nhif.or.tz/).

The medical system in Tanzania is overstretched, particularly in certain regions. Service is not as effective in rural compared to urban areas. Some health facilities are not well organized due to untrained health providers. A recent survey of health facilities in 2012 and 2013 highlighted a lack of adequate diabetes care in most of them [12]. Some trained providers are not working exclusively in the pediatric clinics, meaning that children and adolescents with T1DM receive their diabetes care in adult clinics and/or must buy the medication. A single vial of human insulin costs around 20,900 Tanzanian shillings (Tshs) (= 9 US dollars). It is a suboptimal situation for many patients.

Type 1DM is a chronic condition that requires day to day attention and severely affects quality of life (QoL), in youth [13-14]. This is compounded by a lack of resources (employment, income). Children and adolescents face many challenges (psychological effects of the condition such as stigma and health challenges). Indeed, poverty, which is seen as one of the major social determinants of health in Tanzania, may affect the overall behavior and emotion of the patients and, in turn, their QoL [15].

Little information exists on HR-QoL in Tanzania in patients with diabetes and on the modifiable risk factors that could potentially be addressed [16]. We believe that to improve diabetes care in Tanzania, we need to not only understand the diabetes related QoL in youth with diabetes but also to understand whether T1DM affects the QoL of their parents and whether there is a difference between the overall QoL of youth with and without diabetes. prose

The specific objectives of our study were: 1. to assess the diabetes-specific health-related QoL (HR-QoL) of children and adolescents with T1DM and compare it with the perception of their parents and 2. to compare the overall QoL of children and adolescent patients with T1DM with the QoL of children and adolescents without T1DM.

Therefore, we hypothesized that diabetes and its management negatively affect HR- QoL not only in youth, but also in their parents and that the general QoL of youth with a chronic disease such as T1DM would be lower than in peers without diabetes.

MATERIALS AND METHODS

Study design and date: A cross sectional study conducted between August to October 2020.

Study setting: The study was performed in three rural areas in South Central Tanzania: Ifakara (population 600,000), Iringa (population 941,238) and Mbeya (population of 2,707, 410). Patients are referred to the main referral hospitals of three regions that are close geographically and share a similar social, cultural, and economic environment: St Francis Hospital (SFRH, Ifakara), Iringa Regional Hospital (IRH, Iringa) and Mbeya Hospital (Mbeya). Iringa is 312 km (6 ½ hours per road) west of Ifakara and Mbeya is located a further 620 km west of Iringa (11 hours by road). In the 3 areas, farming is the main socioeconomic activity, with most of the community being small-scale farmers. The first language of the patients is Swahili.

Like the general population, most families do not have Government-funded health insurance. In short, our programs organize weekly/monthly visits for children and adolescents with T1DM in the three centers. Children under 12 years attend the clinic with at least one caretaker (parent or other family member) while older youth often come by themselves. Although we aim to see patients quarterly, for various reasons, including lack of transportation, some patients come less often. Our team includes a nurse, a part-time dietitian (shared with other programs) and is led by a physician (pediatric endocrinologist or general pediatrician/medical doctor with expertise in diabetes). Individual diabetes education is offered monthly by a nurse with options for group education in one center (Mbeya). Since 2009, patients have been provided during the clinic visit with human insulin (short acting, intermediate acting and premix), glucose strips (two per day) and glucometers received from the LFAC or CDiC programs. Urine strips are not available. HbA1c determination is performed as often as possible but is not always available.

Study population: A convenience sample of children and adolescents with T1DM who attend the SFRH, IRH or Mbeya hospitals and are enrolled in the CDiC and LFAC programs. Patients were recruited consecutively upon registration at the clinic over the duration of the study. To compare the perception of T1DM by the children/adolescents and their parents, parents of the patients with diabetes were also recruited.

To compare the overall QoL of children and adolescents with and without diabetes, we also recruited in the community a control group of children and adolescents of the same age and sex. Questionnaires were administered to the control group to confirm the absence of T1DM or other chronic condition by eliciting information on their health status.

The research was approved by the local district health Government offices (Iringa District and Kilombero District) and informed consent/assent was received according to local customs: informed consent was received in writing or verbally, depending on the education of the parents. Assent was received from children aged 14 and above. The study was explained in Swahili.

Data collection: The following demographic data were collected from participating children and adolescents and their parents: age, education, and sex. In addition, we asked for the occupation of the parents and for the estimated family income. Monthly family income was defined as high (greater than 2800000 Tshs = 1212 USD), moderate (between 200100 Tshs and 2800000 Tshs) or poor (less than 200100 Tshs = 87 USD).

For the first objective of the study, diabetes-related QoL was assessed in the participants using translated validated PedsQL™ questionnaires specific to children (7-13 years) and adolescents (14-17 years) with T1DM and to parents [17-18]. In short, these questionnaires enquire on key areas of QoL including diabetes, treatment of diabetes, worry about diabetes and communication with others. The participant answers each question as "never, almost never, sometimes, often, almost always". The researcher asked the participants to answer the questions based on their perception during the last month.

For the second objective of the study, assessment of the general QoL of children and adolescents with and without diabetes was performed Kid-KINDL® and the Kiddo-KINDL® questionnaires [19]. In short, The KINDL® is a generic instrument for assessing Health-Related Quality of Life in children and adolescents through 24 questions on key areas of overall QoL including general feeling, feeling on physical health, about oneself, about the family, friends and school. The participant answers each question as "never, seldom, sometimes, often, all the time".

A trained research team administered the questionnaires in person. Training took place in English and Swahili during the month before the initiation of data collection and included the following topics: consenting, asking the questions and filling in questionnaires. In most of the cases, questions were read by the researcher to the families due to lack of education. A follow-up cell phone communication took place if clarifications of the answers were needed.

Support for insulin and transportation costs were offered to families as an incentive when needed. This happened either at the time of recruitment or at the end of the interview.

Statistical analysis: Descriptive analysis was used to present the HR-QoL in youth with diabetes. A non-parametric Wilcoxon signed-rank test was used for the comparison of the HR-QoL between youth with T1DM and their parents. The comparison between the general QoL of youth with and without diabetes was performed using a Fisher test. A $p < 0.05$ was considered as significant.

RESULTS

Twenty-one children and adolescents with T1DM aged 7-13 and 14-17 years participated in the study and completed

both a HR-QoL (PedsQL™) and a general QoL questionnaire (KINDL®).

Table 1: Characteristics of children and adolescents who participated in the study and of their parents.

	Patients with diabetes	Controls
Children and adolescents		
Age		
Children 7-13 years		
N (%)	9 (43)	10 (48)
mean (SD)	10.6 (1.6)	8.3 (1.6)
median (range)	10 (8-13)	7.5 (7-11)
Adolescents 14-17 years		
N (%)	12 (57)	11 (52)
mean (SD)	15.5 (1.1)	15.6 (1.3)
median (range)	16 (14-17)	15 (14-17)
Sex		
Male	11 (52%)	10 (48%)
Female	10 (48%)	11 (52%)
Education		
None	0 (0%)	0 (0%)
Preschool	0 (0%)	0 (0%)
Primary	6 (29%)	7 (33%)
Secondary	15 (71%)	14 (67%)
Parents		
Age (yrs)		
20-39	1 (6%)	13 (86.7%)
40-49	7 (47%)	2 (13.3%)
>49	7 (47%)	0 (0%)
Sex		
Males	9 (60%)	0 (0%)
Females	6 (40%)	15 (100%)
Education		
None	4 (26.7%)	1 (6.7%)
Primary	10 (66.7%)	12 (80%)
Secondary	0 (0%)	2 (13.3%)
College	1 (6.7%)	0 (0%)
Occupation		
Farmer/peasant	9 (60%)	8 (53.3%)
Business/employee	2 (13.3%)	3 (20%)
Petty trader	4 (26.7%)	4 (26.7%)
Income		
High	3 (20%)	0 (0%)
Moderate	9 (60%)	9 (60%)
Poor	3 (20%)	6 (40%)

In addition, for the first objective of the study, parents of the patients with T1DM were asked to complete the HR-QOL questionnaire (PedsQL™). Only 15 parents participated and data of only 15 pairs of children and adolescents with diabetes and their parents were thus available for analysis.

For the second objective of the study, a control group of children and adolescents of the same age and sex as the patients with T1DM from families with similar occupations and incomes was also recruited and completed a general QoL questionnaire (KINDL®). The characteristics of the population under study are described in Table 1.

Objective 1: Assessment of the health-related Quality of life (HR-QoL) of children and adolescents with diabetes and comparison with the perception of their parents

We divided the questions included in the questionnaire as follows: signs and symptoms associated with diabetes (Supplemental material, Appendix 1), the management of diabetes (Supplemental material, Appendix 2), interactions with health professionals (Supplemental material, Appendix 3) and communication with family and other people (Supplemental material, Appendix 4).

Overall, HR-QoL complaints reported "often" or "almost always" by more than 25% of the children and adolescents with T1DM included frequent urination (27%), abdominal pain (27%) and being tired (27%). Patients with T1DM also reported that it was hard to exercise (26%), to track carbohydrates (33%), to carry a fast-acting carbohydrate (33%) and to snack when "low" (40%). They worried about going "low" (40%), "high" (33%) and about whether the medical treatments are working (33%). They expressed difficulties with explaining their illness to other people (33%) and were embarrassed about having diabetes (27%).

For each question in each theme, there was no statistical difference in the perception of issues related to diabetes between children/adolescents and their parents.

Objective 2. Comparison of the general QoL of children and adolescent patients with T1DM with the general QoL of children and adolescents without T1DM

We compared the general QoL in the 2 groups of 21 children and adolescents with and without diabetes (See descriptive data in Supplemental material, Appendices 5-10). Themes examined included physical health, overall feeling in general and about themselves, relationships with family and friends, and how they felt about school over the last month. Overall, children and adolescents with diabetes reported a statistically significant lower quality of life in most domains compared to children and adolescents without diabetes.

Physical health

Children and adolescents with diabetes felt sicker ($p=0.004$) and had less energy ($p=0.0009$) than controls. Self-image was most affected: they were less proud of themselves ($p=0.0002$), did not feel as much on top of the

world (p=0.0001), were not pleased with themselves (p=0.0001) and did not think they had as good ideas as children and adolescents without diabetes (p=0.0005).

General feeling

Children and adolescents with diabetes were more often scared and unsure of themselves compared to controls (p=0.04).

Relationship with family

Although in both groups, the majority got on well with their parents and felt fine at home (NS), children and adolescents with diabetes quarreled more often at home (p=0.01) and felt more restricted by their parents (p=0.002) compared to controls.

Relationship with friends

Relationship with friends was affected by diabetes and children and adolescents with diabetes felt that they did not do as many things together with their friends (p=0.001), had less success with their friends (p=0.0002), did not get along well with their friends (p=0.005) and felt different from other people (p=0.00004) compared to controls.

Schooling

School was also affected by diabetes. Children and adolescents with diabetes had more difficulty doing the schoolwork (p=0.02), did not find school as interesting (p=0.00003) and worried more about getting bad marks or grades (p=0.001).

DISCUSSION

Our results show that T1DM similarly affects the HR-QoL of children and adolescents and of their parents. In addition, children and adolescents with T1DM have a general QoL that is lower than the QoL of children and adolescents without T1DM.

Several authors have shown that diabetes-specific HR-QoL is negatively affected in children and adolescents [20-22]. Others did not observe such an effect [23]. In a recent study performed in Ethiopia, a Low- and Middle-income country located in the same part of Africa as Tanzania, children, and adolescents with T1DM were found to have a relatively good HR-QoL. However, higher HR-QoL was associated with better parental education, having an employed father and frequent blood glucose monitoring [24]. Recently, the TEEN study which took place in 20 different countries across 5 continents and included almost 6000 children, adolescents and young adults with diabetes also observed a large variability of the HR-QoL in their population. Several characteristics were associated with a better HR-QoL, including lower HbA1c, greater education of the parents and higher income. Although causality was not demonstrated, these recurrent observations raise the possibility that HR-QoL depends at least in part on modifiable factors [25]. In our study, more than a quarter of our participants reported major concerns with specific areas of the HR-QoL. Our patients only had access to basic management tools (human short acting, intermediate acting or premix insulin and limited blood glucose monitoring with some shortages due to delays in reaching the clinic). Most (93%) of the families had no or primary school level education. Whether better diabetes care and a higher level of education would lead to a better HR-QoL in Tanzanian youth remains to be determined.

We observed that parents of children and adolescents with T1DM had a similar perception of the HR-QoL as reported by their children. In two studies (one in Greece and one in Tunisia), parents felt that their children were more affected by diabetes than the children reported themselves [26-27]. The reason for this difference is unclear although patients in Greece and Tunisia had better access to care than in Tanzania. A recent study in Germany investigated the relationship between under and over estimation by caregivers of the QoL of their children with T1DM. Caregivers overestimated the QoL of their children more often than the contrary. There was a relationship between the direction of the discrepancy and positive screening for depression in both children and caregivers. Youth who screened positive for depression were at higher risk of their QoL being overestimated by caregivers than youth who screened negative for depression. Caregivers who screened positive for depression overestimated the QoL of their children less often than caregivers who screened negative for depression [29]. Taken together, these data highlight the importance of understanding the direction of the discrepancy between the perception of HR-QoL in children and caregivers.

Finally, we compared the general QoL in children and adolescents with and without T1DM of similar sex and age and living in the same area. Children and adolescents with diabetes reported a lower general QoL compared to health controls in many domains. Data from the literature are variable. Some authors reported a similar overall QoL in youth with and without T1DM [23, 28, 30]. In an analysis of 33 articles, Nieuwsteeg, et. al found that on average, general QoL was similar in youth with and without T1DM, although there was a lot of variability [31]. We hypothesize that many modifiable factors, such as

bias, level of care, education make understanding of the factors leading to lower, similar or higher general QoL of this chronic condition very difficult.

Our study has several strengths. First, our study took place in a very rural area of Tanzania contrasting with most studies that take place in academic centers and urban areas. Second, we compared the general QoL to the general QoL of a control group from the same region, not from literature data. Our study also has several limitations. First, the characteristics of the families of the children and adolescents with and without diabetes were different. The parents of children without diabetes were younger, they were represented by their mother and the average income was somewhat higher (Table 1). Whether these differences influenced the comparison of the 2 groups of children is unknown. Second, the size of our study and control groups was relatively small, making in-depth analysis of the data difficult.

CONCLUSION

The results of our study show that QoL of life of children and adolescents with diabetes remains lower than those without diabetes, and that a significant proportion of patients report low HR-QoL. The characteristics of our study group include factors that have been associated with poor QoL in other studies, including lack of parental education and poverty. Taken together, our data support the need to devote more resources to the management of T1DM in youth. This can potentially be achieved by better health education, community programs that address stigma and bias, greater involvement of the schools and better access to the care of this chronic condition. These results may help Tanzanian health professionals and families to advocate with the Tanzanian Health Authorities for more resources.

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Authorship

JCB and JPC developed the study protocol; JK, EK, RE and HS have contributed equally to the implementation of the study and to the data management and analysis; JCB, EK and JPC wrote the manuscript and all authors agreed on authorship and on the final version of the manuscript.

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Supplemental material, Appendix 1: Comparison between children and adolescents with T1DM and their parents on the assessment of signs and symptoms associated with diabetes.

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N (%)		Never	Almost never	Sometimes	Often	Most of the time	P
Feeling hungry	D	3 (20)	6 (40)	4 (26)	1 (7)	1 (7)	0.61
	P	2 (13)	6 (40)	4 (26)	2 (13)	1 (7)	
Feeling thirsty	D	1 (7)	6 (40)	5 (33)	2 (13)	1 (7)	1
	P	1 (7)	6 (40)	5 (33)	2 (13)	1 (7)	
Frequent urination	D	1 (7)	6 (40)	4 (26)	3 (20)	1 (7)	0.33
	P	2 (13)	6 (40)	3 (20)	3 (20)	1 (7)	
Frequent stomachache	D	3 (20)	7 (47)	1 (7)	3 (20)	1 (7)	0.71
	P	2 (13)	7 (47)	2 (13)	3 (20)	1 (7)	
Frequent headache	D	4 (26)	4 (26)	5 (33)	1 (7)	1 (7)	0.64
	P	3 (20)	4 (26)	5 (33)	2 (13)	1 (7)	
Feeling like she/he needs to throw up	D	10 (67)	4 (26)	0 (0)	1 (7)	0 (0)	0.80
	P	11 (74)	2 (13)	2 (13)	0 (0)	0 (0)	
Feeling low	D	5 (33)	6 (40)	2 (13)	1 (7)	1 (7)	0.33
	P	4 (26)	6 (40)	3 (20)	1 (7)	1 (7)	
Tired	D	0 (0)	7 (47)	4 (26)	3 (20)	1 (7)	1
	P	0 (0)	7 (47)	4 (26)	3 (20)	4 (26)	
Shaking	D	4 (26)	5 (33)	3 (20)	1 (7)	2 (13)	0.70
	P	4 (26)	4 (26)	2 (13)	2 (13)	3 (20)	
Sweating excessively	D	5 (33)	6 (40)	1 (7)	1 (7)	2 (13)	1
	P	4 (26)	7 (47)	2 (13)	0 (0)	2 (13)	
Dizzy	D	7 (47)	5 (33)	2 (13)	0 (0)	1 (7)	0.61
	P	5 (33)	7 (47)	2 (13)	0 (0)	1 (7)	
Feeling weak	D	4 (26)	3 (20)	6 (40)	0 (0)	2 (13)	0.91
	P	3 (20)	5 (33)	4 (26)	0 (0)	3 (20)	
Trouble with sleeping*/Insomnia**	D	6 (40)	4 (26)	5 (33)	0 (0)	0 (0)	0.85
	P	6 (40)	4 (26)	5 (33)	0 (0)	0 (0)	
Irritability*/ Getting cranky**	D	8 (53)	3 (20)	1 (7)	2 (13)	1 (7)	0.82
	P	7 (47)	4 (26)	1 (7)	2 (13)	1 (7)	

P value (non-parametric Wilcoxon signed-rank test)
*Definition used for children aged 7-13 years
**Definition used for children 14-17 years
D: Children and adolescents with diabetes; P: Their parents
N = 15. The same percentage has been attributed to each N value and the total percentage therefore varies from 98 to 101%

Supplemental material, Appendix 2: Comparison between children and adolescents with T1DM and their parents on issues associated with the management of diabetes.

		Never	Almost never	Sometimes	Often	Most of the time	P
It is hard to take blood glucose tests	D	1(7)	4(26)	8(53)	1(7)	1(7)	0.80
	P	1(7)	3(20)	9(60)	1(7)	1(7)	
It is hard to take insulin shots	D	1(7)	5(33)	6(40)	2(13)	1(7)	0.39
	P	0	3(20)	9(60)	2(13)	1(7)	
It is hard to exercise or do sports	D	2(13)	4(26)	5(33)	2(13)	2(13)	0.58
	P	2(13)	3(20)	4(26)	3(20)	3(20)	
It is hard to track carbohydrates	D	1(7)	5(33)	4(26)	3(20)	2(13)	0.73
	P	2(13)	5(33)	4(26)	1(7)	3(20)	
It is hard to carry a fast-acting carbohydrate	D	2(13)	2(13)	6(40)	4(26)	1(7)	0.93
	P	2(13)	2(13)	6(40)	3(20)	2(13)	
It is hard to snack when he/she goes "low"	D	2(13)	2(13)	5(33)	5(33)	1(7)	0.95
	P	2(13)	2(13)	6(40)	3(20)	2(13)	

P value (non-parametric Wilcoxon signed-rank test)
D: Children and adolescents with diabetes; P: Their parents
N = 15. The same percentage has been attributed to each N value and the total percentage therefore varies from 98 to 101%

Supplemental material, Appendix 3: Comparison between children and adolescents with T1DM and their parents on the worries associated with having diabetes.

		Never	Almost never	Sometimes	Often	Most of the time	P
Worrying about going "low"	D	1 (7)	4 (26)	4 (26)	6 (40)	0 (0)	0.51
	P	0 (0)	3 (20)	5 (33)	7 (47)	0 (0)	
Worrying about going "high"	D	2 (13)	4 (26)	4 (26)	4 (26)	1 (7)	0.22
	P	5 (33)	5 (33)	1 (7)	3 (20)	1 (7)	
Worrying about whether or not medical treatments are working	D	1 (7)	6 (40)	3 (20)	5 (33)	0(0)	0.53
	P	0 (0)	6 (40)	3 (20)	5 (33)	1 (7)	
Worrying about long-term complications from diabetes	D	5 (33)	3 (20)	4 (26)	0 (0)	3 (20)	0.59
	P	4 (26)	2 (13)	5 (33)	1 (7)	3 (20)	

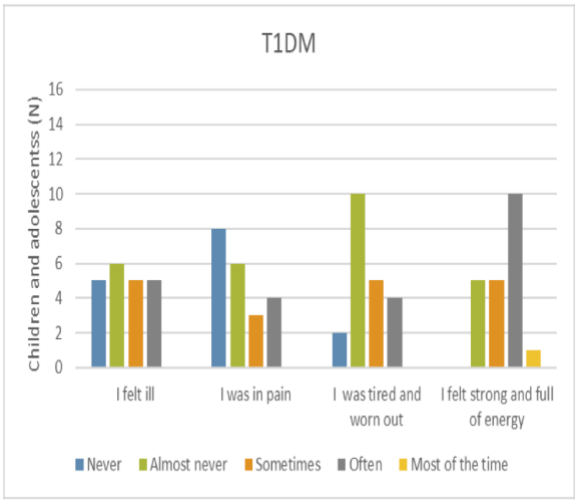
P value (non-parametric Wilcoxon signed-rank test)
D: Children and adolescents with diabetes; P: Their parents
N = 15. The same percentage has been attributed to each N value and the total percentage therefore varies from 98 to 101%

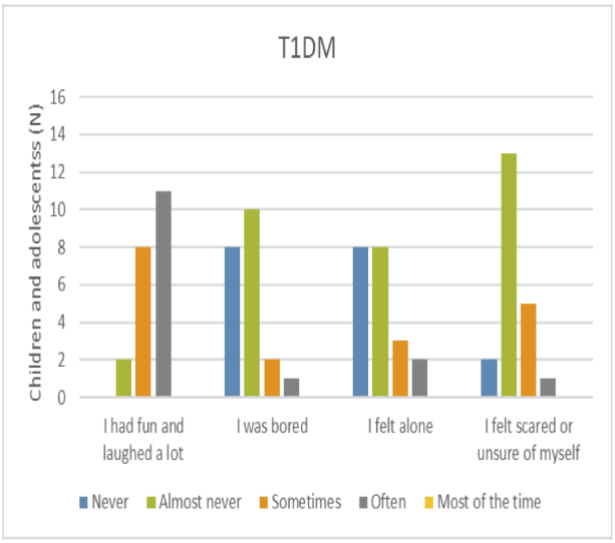
Supplemental material, Appendix 4: Comparison between children and adolescents with T1DM and their parents on communication issues associated with the management of diabetes.

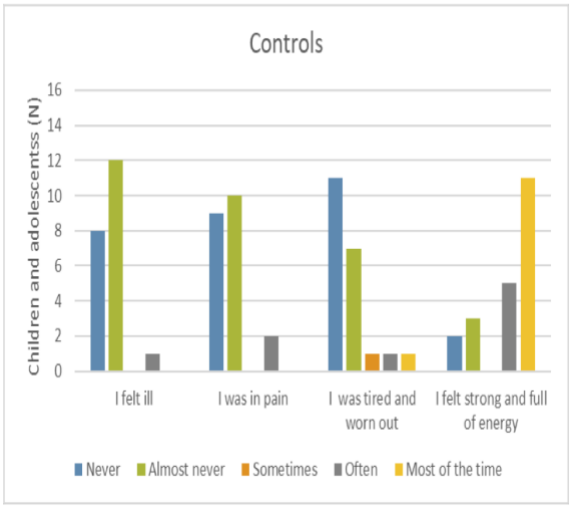
		Never	Almost never	Sometimes	Often	Most of the time	P
Telling the doctors and nurses how they feel	D	3(20)	4(26)	5933)	2(13)	1(7)	0.86
	P	3(20)	5(33)	4(26)	2(13)	1(7)	
Asking the doctors or nurses questions	D	4(26)	5(33)	6(40)	0(0)	0(0)	1
	P	4(26)	5(33)	6(40)	0(0)	0(0)	
Explaining their illness to other people	D	4(26)	3(20)	3(20)	4(26)	1(7)	0.78
	P	4(26)	3(20)	5(33)	2(13)	1(7)	
Getting embarrassed about having diabetes	D	3(20)	3(20)	5(33)	3(20)	1(7)	0.68
	P	3(20)	3(20)	7(47)	2(13)	0(0)	

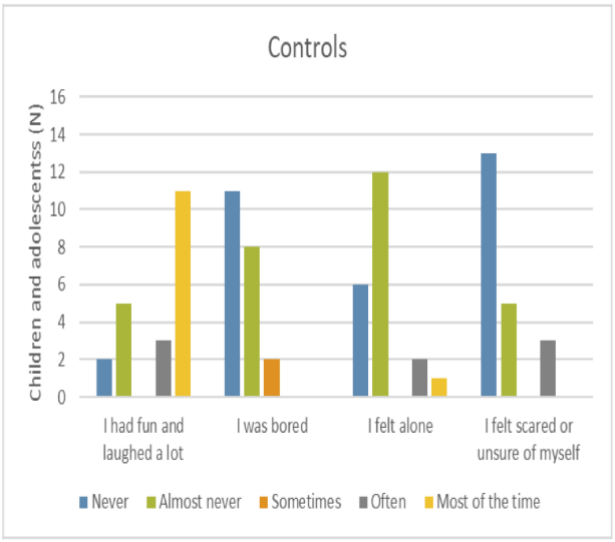
P value (non-parametric Wilcoxon signed-rank test)
D: Children and adolescents with diabetes; P: Their parents
N = 15. The same percentage has been attributed to each N value and the total percentage therefore varies from 98 to 101%

Supplemental material, Appendix 5:
Descriptive data on how children and adolescents with T1DM (top) and in controls (bottom) perceive their physical health.



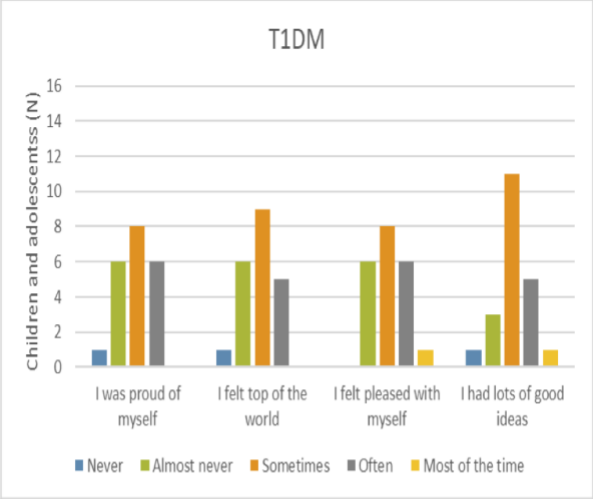


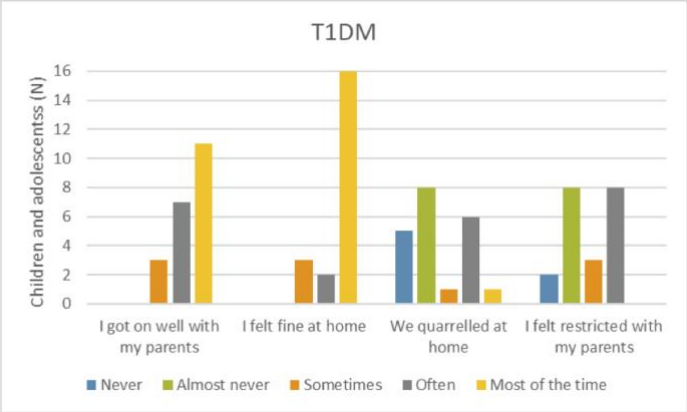


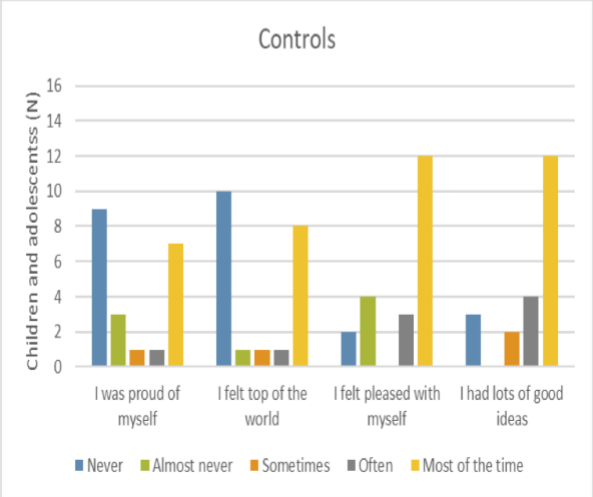


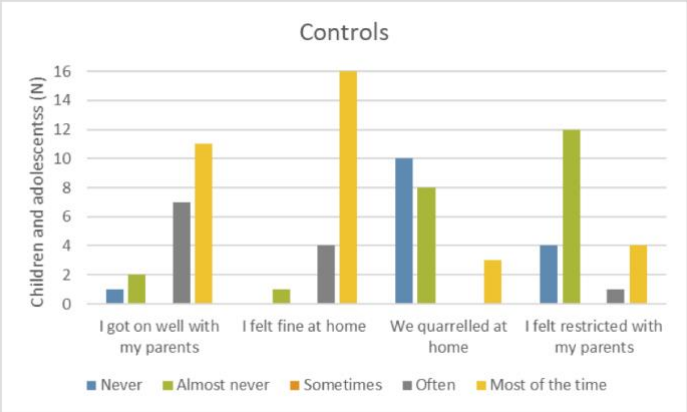
Supplemental material, Appendix 6:
Descriptive data on how children and adolescents with T1DM (top) and controls (bottom) are feeling in general.

Supplemental material, Appendix 7:
Descriptive data on perception of how children and adolescents with T1DM (top) and controls (bottom) are feeling about themselves.





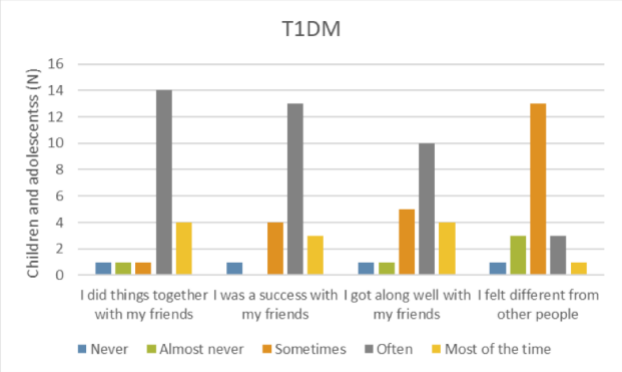


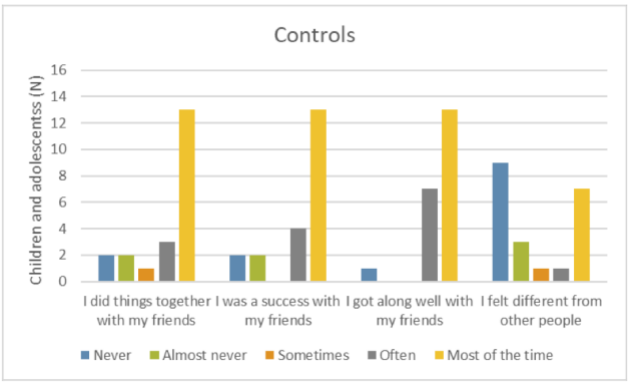


Supplemental material, Appendix 8:
Descriptive data on perception of how children and adolescents with T1DM (top) and controls (bottom) are feeling about themselves.

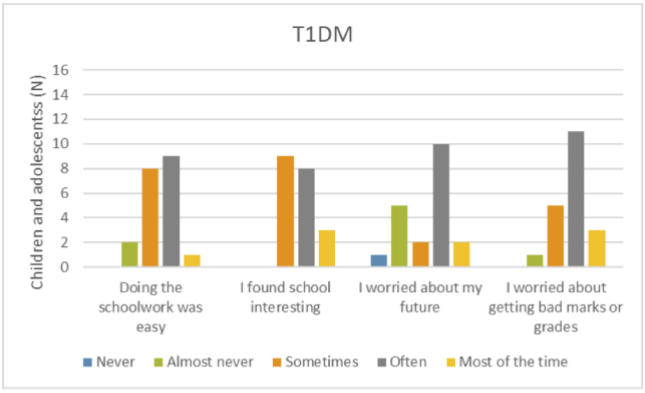
Supplemental material, Appendix 9:

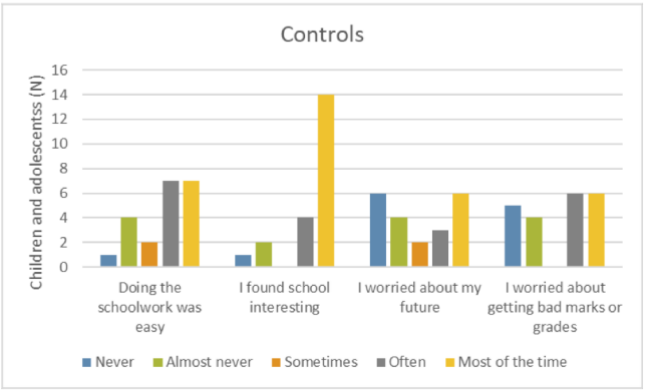
Descriptive data on perception of how children and adolescents with T1DM (top) and controls (bottom) are feeling about the relationship with their family.





Descriptive data on perception of how children and adolescents with T1DM (top) and controls (bottom) are feeling about school.





Supplemental material, Appendix 10: