Original Article

doi: https://doi.org/10.1590/1983-1447.2024.20230251.en

Quality of life related to the clinical and sociodemographic profile of adolescents with type 1 diabetes

Qualidade de vida relacionada ao perfil clínico e sociodemográfico de adolescentes com diabetes tipo 1

Calidad de vida relacionada con el perfil clínico y sociodemográfico de adolescentes con diabetes tipo 1

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How to cite this article:
Lucca M, Lima KT, Ramalho ELR, Pessoa MAS, Sparapani VC, Liberatore Junior RDR, et al. Quality of life related to the clinical and sociodemographic profile of adolescents with type 1 diabetes. Rev Gaúcha Enferm. 2024;45:e20230251. https://doi.org/10.1590/1983-1447.2024.20230251.en

ABSTRACT

Objective: To describe the clinical and sociodemographic profile and associate them with the quality of life of adolescents with type 1 diabetes mellitus being followed up in a public hospital in an inner city of the state of São Paulo.

Method: Quantitative, cross-sectional, and analytical study, performed with 80 dyads. Data were collected through a clinical/sociodemographic form and a Quality of Life Instrument. For analysis, descriptive statistics were used, and Pearson's Chi-square and Fisher's Exact tests were applied to assess the association between quality of life and clinical/sociodemographic variables.

Results: Out of the total participants, the ones who scored high quality of life were mostly, female (52.5%), in the age group 15 to 17 years old (56.3%), 51.3% self-identified as white, and 40.1% were attending high school. In the preoccupation domain, a significant association was found to the time since diagnosis (p=0.035), demonstrating that young adolescents with a longer time of diagnosis had a worse quality of life.

Conclusion: The majority of adolescents in this study (51.3%) had been living with diabetes for 10 or more years. It was identified that the duration of the diagnosis has the potential to interfere with the quality of life of these young individuals.

Descriptors: Adolescent. Diabetes mellitus, type 1. Quality of life. Health profile. Pediatric nursing.

RESUMO

Objetivo: Traçar o perfil clínico e sociodemográfico de adolescentes com diabetes mellitus tipo 1 em seguimento em um hospital público do interior paulista e associá-lo à qualidade de vida.

Método: Estudo quantitativo, transversal e analítico, realizado com 80 díades: adolescentes e seus respectivos responsáveis. Os dados foram coletados através de formulário clínico/sociodemográfico e do Instrumento de Qualidade de Vida para Jovens com Diabetes. Para a análise de dados, utilizou-se estatística descritiva e, para verificar a associação entre a qualidade de vida e as variáveis clínicas e sociodemográficas, aplicaram-se os testes Qui-quadrado de Pearson e o Exato de Fisher.

Resultados: Do total dos adolescentes,52,5% eram do sexo feminino e 56,3% estavam na faixa etária de 15 a 17 anos,51,3% autodeclararam-se brancos e 40,1% cursavam o ensino médio. Os adolescentes apresentaram alta qualidade de vida. No domínio preocupação, entretanto, constatou-se associação significativa com o tempo de diagnóstico (p=0,035), demonstrando que os jovens com mais tempo de doença apresentaram pior qualidade de vida.

Conclusão: A maior parte dos adolescentes deste estudo (51,3%) tinha 10 ou mais anos convivendo com a diabetes. Identificou-se que o tempo de diagnóstico é potencialmente capaz de interferir na qualidade de vida desses jovens.

Descritores: Adolescente. Diabetes mellitus tipo 1. Qualidade de vida. Perfil de saúde. Enfermagem pediátrica.

RESUMEN

Objetivo: Describir el perfil clínico y sociodemográfico y asociarlo con la calidad de vida de adolescentes con diabetes mellitus tipo 1 en seguimiento en un hospital público del estado de São Paulo.

Método: Estudio cuantitativo, transversal y analítico, realizado con 80 diadas. Los datos fueron recogidos mediante un formulario clínico/sociodemográfico y un Instrumento de Calidad de Vida. Se utilizó estadística descriptiva y se aplicaron las pruebas de Chi-cuadrado de Pearson y Exacto de Fisher para verificar la asociación entre la calidad de vida y las variables clínicas/sociodemográficas.

Resultados: Del total de adolescentes,52,5% eran del sexo femenino y 56,3% se encontraban en el grupo de edad de 15 a 17 años, el 51,3% se autodeclararon como blancos y el 40,1% asistían a la escuela secundaria. Los adolescentes presentaron una alta calidad de vida. En el dominio preocupación, se encontró asociación significativa con el tiempo desde el diagnóstico (p=0,035), demostrando que los jóvenes con más tiempo del diagnóstico presentaron peor calidad de vida.

Conclusión: La mayoría de los adolescentes en este estudio (51,3%) llevaban 10 años o más conviviendo con la diabetes. Se identificó que la duración del diagnóstico tiene el potencial de interferir en la calidad de vida de estos jóvenes.

Descriptores: Adolescente. Diabetes mellitus tipo 1. Calidad de vida. Perfil de salud. Enfermería pediátrica.

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INTRODUCTION

Type 1 diabetes mellitus (T1DM) is a chronic, autoimmune disease resulting from the destruction of pancreatic beta cells, resulting in a deficiency in insulin production[1]. Worldwide, there are approximately 1.5 million children and adolescents (0-19 years old) with T1DM, and in Brazil, approximately 112,240 prevalent cases of children and adolescents with diabetes were recorded in 2022[1–2].

T1DM treatment consists of three pillars: insulin therapy, monitoring, and health education, which includes frequent physical activity and a healthy diet[2]. These conditions are intrinsically correlated with glycemic control and, consequently, quality of life[3]. According to the World Health Organization (WHO), quality of life (QoL) refers to an individual's perception of their own life, relationships, culture, values, expectations, standards, and goals that surround them. Furthermore, it is related to the individual's social environment, with repercussions on their physical and psycho-emotional well-being[4]. Treatment of DM1 requires flexibility and changes in habits that may be difficult for young people to follow and, therefore, result in lower adherence to treatment, reduce its effectiveness or culminate in future problems and worsening of QoL[5].

Changes in routine during adolescence can be even more complicated, since, at this stage, people with DM1 need to self-manage their disease and deal with issues inherent to their age group, such as self-esteem, acceptance and independence, which makes this stage of the life cycle even more challenging[6]. Furthermore, sociodemographic[7] and clinical conditions can also interfere with the individual's perception of the disease and the way in which these young people experience this reality[3]. Studies show that adolescents from lower economic classes are more vulnerable to damage caused by DM1, since the opportunities for a good outcome of the disease are smaller, with the risk of ineffective glycemic control and worsening of QoL[8–9]. A study conducted in Ethiopia demonstrated better QoL when parents were educated, in the presence of income associated with parental occupation and frequent blood glucose monitoring, resulting in access to resources[10].

DM1 is a disease that also affects family dynamics, due to conflict situations generated by changes in routine, overload of tasks and financial impacts, sometimes with negative repercussions on treatment and living with the disease[11]. Therefore, it is necessary that, in the planning of each case, family issues and their demands are met, since the family is the main support and support for these adolescents and plays an important role in the implementation and continuity of the therapeutic plan, avoiding future complications[11].

The assessment of QoL related to the clinical and sociodemographic profile of adolescents with T1DM is important, as it systematizes valuable information about the life context of this clientele, as well as the vulnerabilities and nuances presented by this population group, in order to support proposals for qualifying care and guide the planning of specific interventions. Thus, this study becomes relevant to expand knowledge and subsidize the implementation of conducts that improve the QoL of these patients. Thus, the question is: what social and clinical characteristics of adolescents with T1DM can be related to their quality of life? Given this context, the present study aimed to outline the clinical and sociodemographic profile of adolescents with type 1 diabetes mellitus being followed up in a public hospital in an inner city of the state of São Paulo and associate it with QoL.

METHOD

This is a quantitative, cross-sectional, and analytical study, guided by the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) framework, developed at the pediatric endocrinology outpatient clinic of a public teaching hospital located in the interior of the state of São Paulo, Brazil. This health institution is characterized as a reference center for the treatment and monitoring of adolescents with T1D.

Using a non-probabilistic convenience sample, 98 dyads (adolescents and their respective guardians) were approached. Of these, 18 dyads did not agree to participate or did not meet the eligibility criteria established for the study, resulting in 80 families eligible for the study.

The study included adolescents diagnosed with T1D together with their parents or caregivers, herein described as dyads. Adolescents aged 12 to 18 years old, from both gender, who had been diagnosed with T1D for at least six months and were using insulin therapy, participated in the study. Adolescents who were not accompanied by a legal guardian at the time of data collection and those who were unable to read or respond to the QoL instrument due to some cognitive, physical, or mental difficulty were excluded. These young people were excluded because the QoL instrument was self-administered, and the standardization of data collection did not allow interviewers to read the instrument to participants. Initially, the lists of potential participants were made available by the health service through prior contact with the responsible medical team. Then, the researchers, duly trained and qualified to administer the instruments and under the supervision of senior researchers, recruited participants at the aforementioned outpatient clinic twice a

week, while they were waiting for their medical appointment. The average number of appointments at this service was 12 adolescents per day. Contact with potential participants was also made remotely, through telephone calls made possible by the health service by providing the telephone numbers of the adolescents' guardians. Initially, a text message was sent via WhatsApp® explaining the objectives of the research and inviting them to participate. If they accepted, they arranged a date and time with the researcher for the call, at which time the objectives, nature, procedures and instruments used in the research were clarified again, as well as any doubts resolved, prior to the start of data collection with the adolescents and their guardians separately. The Informed Consent Form (ICT) for both adolescents and their guardians were duly signed after acceptance to participate in the study; in both forms of collection, the terms were signed using a form made available online. Data collection took place from May 2021 to February 2022, in person and/or remotely, the latter being carried out due to the impossibility of a face-to-face meeting, due to restrictions in the context of the COVID-19 pandemic or due to the participants' preference.

Two instruments were used to collect data. The first was a form regarding clinical and sociodemographic profiles, prepared by members of a research group on DM1, of which the authors are members, based on a literature review and periodic meetings with experts in diabetes education. This form contains 76 questions about clinical and sociodemographic profiles, insulin therapy, blood glucose monitoring, nutritional aspects, physical activity, acute and long-term complications. These data were self-reported by the adolescents, together with their guardians, and collected in the electronic medical record, with their authorization. The clinical and sociodemographic variables studied were: gender, marital status of guardians, education level of guardians, monthly income, time since diagnosis, physical activity and glycated hemoglobin level. The second was a self-administered instrument called the Quality of Life Instrument for Young People with Diabetes (QoLIYPK), developed by Ingersoll and Marrero (1991), originally in English and validated for Brazilian culture in 2004[11]. The QoLIYPK[11] contains 50 questions, arranged in three domains: A. Satisfaction (17 questions); B. Impact (22 questions); and C. Concern (11 questions). All questions are of the Likert type, with five answer options. In the Satisfaction domain, the answers range from very satisfied to very dissatisfied. In the Impact and Concern domains, from never to always. The total and domain scores are calculated by summing, in which the lowest score indicates a better Health-Related Quality of Life (HRQoL), except for item B7 of the Impact domain, which is inverted, that is, the lowest score indicates a worse HRQoL. Furthermore, there is a question that involves adolescents' self-perception of their health, the answers to which vary between excellent, good, satisfactory and poor. It is important to note that the QoLIYPK[11] does not have a predefined cut-off point, so the calculations were based on the sample of this study and determined by quartiles, following the precepts of the validation study[11]. To determine these quartiles, the highest score value was subtracted from the lowest value of each domain and the result was divided by four. The value of this division is added to the minimum value of the domain, and, with this, the range of the first quartile is obtained. For example, the Worry domain has the minimum value of 11 and the maximum value of 40, therefore, we have 40-11 = 29 and 29/4 = 7.25; approximately 7. Thus, the first quartile was defined as the range between 11 and 18 (11+7=18), the second comprised the values between 19 and 26 (19+7 = 26) and so on for each range and domain.

To mitigate possible sources of bias during data collection, clear inclusion and exclusion criteria were established for participants, with the purpose of avoiding any bias in sample selection. In addition, the research team was trained to standardize the application of data collection instruments, reducing the possibility of systematic errors. These measures sought to ensure the internal and external validity of the study to guarantee accurate results without distortions arising from potential biases in data collection.

Statistical analysis of the data was performed using IBM® SPSS® Statistics version 25 and R i386 v.3.4.0., adopting a significance level of 5% or less. The values of monthly income (in minimum wage), time since diagnosis (in months) and glycated hemoglobin were compared between the two categories of HRQoL High/Very high and Low/Very low in the domains Satisfaction, Impact and Concern and with the total QOLIYPK scale[11]. Only the variable time since diagnosis showed normality (Kolmogorov-Smirnov test p=0.200), for which the t-test for independent samples was applied and the Mann-Whitney test for the other two variables. To verify the association between HRQoL and clinical and sociodemographic variables, Pearson's chi-square test and Fisher's exact test were applied. In the multivariate analysis, the Poisson regression model with robust variance and a 95% confidence interval was used. The power calculations of the applied analyses were performed using the respective R program packages, called WebPower and pwrss, assuming a medium test size (f2 = 0.15)[12], considering the number of predictors (parameters) in the regression model equal to 10 (p = 10) and the study sample size of 80 participants. This study complied with the ethical recommendations established by

Resolution 466/12 of the National Health Council[13], which guides the development of research involving human beings in the country. All ethical precepts were respected, including the particularities for approaching and conducting research with adolescents, a vulnerable population. The research was approved by the ethics committees of the proposing and co-participating institutions (CAAE: 28312919.2.3003.5440).

RESULTS

Data were collected from 80 dyads – adolescents and their respective caregivers, with 85% of the collections occurring in person and 15% remotely. The application of the form and the HRQoL instrument took approximately 40 minutes.

Data regarding the clinical and sociodemographic profile of 80 adolescents diagnosed with DM1 were analyzed, of which 52.5% were female and 56.3% were between 15 and 17 years old. 51.3% self-identified as white and 40.1% were attending high school. Regarding the time since diagnosis of DM1, 51.3% had been diagnosed with the disease for 10 years or more, 60% did not engage in any type of physical activity, with an average Body Mass Index (BMI) of 21.6, which is considered eutrophic, 90% did not count carbohydrates, and the majority (97.5%) did not participate in any diabetes education group.

Regarding the most used device for insulin administration, 71.3% reported using a disposable pen, 56.3% used NPH insulin (basal type), and 48.8% used regular insulin (bolus type). Most participants (91.3%) were already self-administering insulin, and 63.8% responded that they did not have lipohypertrophy. The average glycated hemoglobin value for the entire sample of participants in the study was 10.1%. The average value for the total number of bolus insulin units administered in one day was 33.2 IU. Regarding hospitalization due to complications of DM1 (ketoacidosis, hyperglycemia, and hypoglycemia), 88.8% did not require hospitalization in the last 6 months. Data from the 80 responsible caregivers were also investigated, and it was found that a large portion (80%) were the mothers of these adolescents. Of the caregivers, 51.3% were married and 42.5% had completed high school. Approximately 31.3% had a formal job, and 54% of the caregivers earned between 1 and 3 minimum wages. Regarding the HRQoL scores obtained through the QoLIYPK instrument[11], it was identified that, in the QoLIYPK Total domain, 71.3% of these young people had a low HRQoL score. In the satisfaction, impact, and concern domains, the HRQoL score was also low, as illustrated in Table 1, showing that the young people in this sample had a high HRQoL. It should be noted that the lower the score, the better the quality of life.

Regarding self-perception of health status, 22.5% of young people with DM1 reported their health as excellent, 47.5% as good, 18.8% as satisfactory and 11.3% as poor.

In this study, the association between the Total QoLIYPK score[11] and variables of the clinical and sociodemographic profile of the adolescents was also made. The analysis of these data did not show any statistically significant association between the variables Total QoLIYPK and sex, Total QoLIYPK and glycated hemoglobin value, Total QoLIYPK and time since diagnosis and Total QoLIYPK and physical activity. The Total QoLIYPK score was also associated with data from the guardians of these young people and, similarly, there was no significant association between Total QoLIYPK and the parents' level of education, Total QoLIYPK with marital status and Total QoLIYPK with income. Table 2 describes the results found.

However, the Worry domain showed a significant association with the variable time since diagnosis, since young people with a longer time since diagnosis had worse HRQoL (T-test p= 0.035) compared to those who were recently diagnosed with DM1 (Table 3).

Table 1 – Quality of life scores of adolescents with DM1, according to QoLIYPK[11] (n=80). Ribeirão Preto, SP, Brazil, 2021-2022

QoLIYPK	Median	Standard deviation	Minimum	Maximum
QoLIYPK- Total	116,8	24,3	76	172
QoLIYPK- Satisfaction	40,7	11,6	22	67
QoLIYPK- Impact	54,4	12,4	36	78
QoLIYPK- Preocupations	26	8,6	11	40

Source: Reserach data (2022)

Table 2 – Association of health-related quality of life with sociodemographic variables of adolescents with DM1, according to QOLIYPK(11) (n=80). Ribeirão Preto, SP, Brazil, 2021-2022

Variable	Quality of life		p-value	Test power
	High/very high	Low/very low		
	n(%)	n(%)		
Gender			0,120**	0,765
Male	22(57,9)	16(42,1)		
Female	17(40,5)	25(59,5)		
Does physical activity			0,258**	0,668
No	16(42,1)	22(57,9)		
Yes	23(54,8)	19(45,2)		
Guardians` Educational background			0,510*	0,668
Incomplete elementary school	6(312,6)	13(68,4)		
Complete elementary school	5(71,4)	2(28,6)		
Incomplete high school	5(45,5)	6(54,5)		
Complete high school	18(58,9)	16(47,1)		
Incomplete higher education	2(66,7)	1(33,3)		
Complete higher education	3(50,0)	3(50,0)		
Guardians` Marital status			0,129*	0,765
Single	6(66,7)	3(33,3)		
Married/Stable Union	22(40,0)	33(60,0)		
Separated/Divorced	8(66,7)	4(33,3)		
Widow	3(75,0)	1(25,0)		

Note: *Fisher's exact test. **Pearson's chi-square.
Source: survey data (2022)

From the multivariate analysis, using Poisson regression with robust variance, we identified no statistically significant association between the outcome variable (High/Very High x Low/Very Low) and the independent variables (gender, age, physical activity, time since diagnosis, glycated hemoglobin, income, education and marital status of guardians) (Tables 4 and 5). The resulting value of the test power was 0.57.

Table 3 – Association between the domains of the quality of life instrument and sociodemographic and clinical variables of adolescents with DM1, according to the QoLIYPK domain[11] (n=80). Ribeirão Preto, SP, Brazil, 2021-2022

Domain/Variable	Minimum/ Maximum	Median	Average	Standard deviation	p	Test Power
SATISFACTION						
Diagnostic time (in months)					0,926†	0.051
High/Very high	-	-	114,4	47,5		
Low/Very low	-	-	115,4	46,7		
Glycated hemoglobin					0,135*	0,441
High/Very high	6,2/19,2	10,1	-	-		
Low/Very low	5,4/17,0	8,7	-	-		
Monthly income (in minimum wages)					0,973*	0,131
High/Very high	350,0/6000,0	2300,0	-	-		
Low/Very low	357,0/8484,0	2500,0	-	-		
IMPACT						
Diagnostic time (in months)					0,821†	0,050
High/Very hight	-	-	116,2	49,6		
Low/Very low	-	-				
Glycated hemoglobin					0,902*	0,053
High/Very high	5,7/19,2	8,7	-	-		
Low/Very low	5,4/17,0	9,2	-	-		
Monthly income (in minimum wages)					0,397*	0,250
High/Very hight	600,0/8484,0	2500,0	-	-		
Low/Very high	350,0/7500,0	2300,0	-	-		
PREOCUPATION						
Diagnostic time (in months)					0,035†	0,525
High/Very high	-	-	127,4	47,7		
Low/Very low	-	-	105,3	44,2		
Glycated hemoglobin					0,070*	0,363
High/Very high	5,5/17,8	8,2	-	-		
Low/Very low	5,4/19,2	9,2	-	-		
Monthly income (in minimum wages)					0,443*	0,078
High/Very high	600,0/8000,0	2300,0	-	-		
Low/Very low	350,0/8484,0	2500,0	-	-		

Table 3 – Cont.

Domain/Variable	Minimum/ Maximum	Median	Average	Standard deviation	p	Test Power
TOTAL						
Diagnostic time (in months)					0,386†	0,010
High/Very high	-	-	119,6	50,3		
Low/Very low	-	-	110,5	43,3		
Glycated hemoglobin					0,263*	0,082
High/Very high	5,5/19,2	8,5	-	-		
Low/Very low	5,4/17,0	9,2	-	-		
Monthly income (in minimum wages)ǂ					0,550*	0,050
High/Very high	700,0/8000,0	2500,0	-	-		
Low/Very low	350,0/8484,0	2300,0	-	-		

Note: †T-test. *Mann-Whitney test. ǂ1 minimum wage = 1.212 *reais*
Source: survey data (2022)

Table 4 – Adjusted values of the Prevalence Ratio, according to Poisson regression for categorical variables (n=80). Ribeirão Preto, SP, Brazil, 2021-2022

Variable	QoLPR high/very high (%)	QoLPR low/very low (%)	PR*	CI(95%)↟	p-value†
Gender			0.80	0,39-1,62	0,535
Female	17 (43.6)	25 (61)			
Male	22 (56.4)	16 (39)			
Phisical Activity			0.86	0,43-1,7	0,664
No	22 (56.4)	26 (63.4)			
Yes	17 (43.6)	15 (36.6)			
Guardians` Educational background					
Elemetary school	11 (28.2)	15 (36.6)	1.14	0,32-4,02	0,838
High School	23 (59)	22 (53.7)	0.96	0,29-3,19	0,941
Higher education	5 (12.8)	4 (9.8)	1		1
Guardians` Marital status					
Married/Stable union	22 (56.4)	33 (80.5)	1		
Divorced/separated/widowed	11 (28.2)	5 (12.2)	0.51	0,18-1,43	0,201
Single	6 (15.4)	3 (7.3)	0.50	0,15-1,7	0,266

Note: *Prevalence ratio. †Wald test. ↟Confidence interval.
Source: survey data (2022)

Table 5 – Adjusted values of the Prevalence Ratio, according to Poisson regression for numerical variables (n=80). Ribeirão Preto, SP, Brazil,2021-2022

Variable	Median	Standard deviation	PR*	CI(95%)↟	p-value†
HIGH/VERY HIGH QUALITY OF LIFE					
Age (years)	15,13	1,54	1,00	0,80-1,26	0,931
Glycated hemoglobin	9,58	3,26	1,04	0,93-1,16	0,477
Time since diagnosis (months)	5,59	4,02	0,99	0,91-1,08	0,811
Income (minimum wages)	2,17	1,18	0,99	0,76-1,29	0,994
LOW/VERY LOW QUALITY OF LIFE					
Age (years)	15,24	1,47	1,00	0,80-1,26	0,931
Glycated hemoglobin	9,95	2,69	1,04	0,93-1,16	0,477
Time since diagnosis (months)	6,17	3,66	0,99	0,91-1,08	0,811
Income (minimum wages)	2,19	1,60	0,99	0,76-1,29	0,994

Note: *Prevalence ratio. †Wald test. ↟Confidence interval.
Source: survey data (2022)

DISCUSSION

This study aimed to outline the clinical and sociodemographic profile and associate it with the quality of life of adolescents with DM1, considering that DM1 is a chronic disease that affects countless young people and can interfere with their quality of life and the way they deal with the disease daily. This group was identified as having a high quality of life in all domains of the QoLIYPK[11], positively evaluating their health status. However, in the concern domain, it was observed that those with a longer time since diagnosis had a lower quality of life, indicating that concerns related to the daily life of an adolescent with DM1 and the fact that the disease interferes with their future life plans negatively affect the quality of life of these young people. No statistically significant associations were found between the variables gender, glycated hemoglobin, time since diagnosis and physical activity with the Total QoLIYPK. The Total QoLIYPK domain showed an association with variables related to caregivers, but no significant associations were identified between the Total QoLIYPK and the parents' level of education, marital status and income. When analyzing the profile of this sample, we identified no significant difference in the prevalence of DM1 diagnosis between the sexes, as verified in studies whose results reported that adolescents of both sexes are equally affected by DM1, as they have the same susceptibility to the disease[1,14]. The results show no significant association between sex and Total QoLIYPK, but it is important to emphasize that, in the scientific literature, the female sex has been associated with worse QoL scores when compared to the male gender[15]. In addition, it is possible to note, in this sample, a higher frequency of low and very low HRQoL scores among girls. A Portuguese study showed that girls were more concerned about issues related to the disease than boys, perhaps because they suffer more hormonal changes during puberty, present more psychological changes at this stage and are more concerned about changes in their image compared to boys[16]. Most of the adolescents in this sample were between 15 and 17 years old and were attending elementary school, which shows a delay in learning, since this level of education is not compatible with their age. This fact was discussed in a study conducted in Marília, in the state of São Paulo, which found that adolescents with chronic diseases have more limitations and difficulties in attending school than their healthy peers, as they require more hospitalizations, suffer

from acute symptoms and, therefore, have higher rates of school absenteeism[17]. Furthermore, a study conducted in Scotland revealed that young people with DM1 have poor educational outcomes, especially those with high levels of average glycated hemoglobin[18].

Regarding the role of caregivers for these adolescents, mothers were considered the main caregivers, assuming an important part of their children's treatment. This idea is reinforced by the still existing social concept of women as caretakers and responsible for home care, including for their children, a fact that often deprives them of work, leisure and rest, resulting in a high physical and emotional burden[9,19]. Therefore, support for these mothers and their needs must be ensured, especially because maternal well-being favors good results in the treatment of DM1[20].

It was evident that, based on the QoLIYPK scores[11], adolescents with DM1 had high HRQoL. Furthermore, the majority (70%) reported excellent/good health, as verified in the current literature[7,15–16]. It is important to highlight that quantitative instruments may not reveal the real perception of these young people regarding what, for them, is quality of life. Furthermore, studies that address quality of life from a subjective perspective can provide advances in the knowledge of the aspects evaluated as important by adolescents throughout their own experiences of illness[21].

In the concern domain of the QoLIYPK[11], there was a significant association with the variable time since diagnosis, highlighting that adolescents with a longer time since diagnosis are more concerned about their condition compared to those who are at the beginning of the disease. This can be explained by the fact that they have lived with the disease for longer and, therefore, feel more emotionally exhausted, and are more likely to experience complications resulting from inadequate management of DM1[7,22–23]. DM1 is a condition that requires self-management, which directly affects the daily lives and social lives of these adolescents, as it interferes with issues such as self-esteem, acceptance and independence, generating feelings such as fear, shame and the need to be accepted, and impacting psychosocial aspects[5].

Although the instrument applied to the population of this study reported high HRQoL, these young people also demonstrated a high median for glycated hemoglobin (10.1%). According to the scientific literature[24], this variable is inversely associated with HRQoL. Glycemic control has been associated with QoL because it interferes with aspects of the daily lives of these young people, and its poor management can lead to hospitalizations and complications that result in distancing from their family, friends and school[22].

Another variable analyzed was the practice of physical activity, which, in this study, did not show a statistically significant association with Total QoLIYPK. However, a US study found that young people who practiced physical exercise obtained high scores for HRQoL and lower glycated hemoglobin in relation to their peers[25]. Furthermore, regular exercise can help control blood sugar levels and is an important part of the treatment of T1DM, since, when combined with other factors, it plays a fundamental role in managing the disease, improving insulin sensitivity and reducing total daily doses, promoting well-being and reducing acute episodes of hyperglycemia, for example, as well as long-term complications[26]. It is noteworthy that most of the adolescents in this study reported being away from physical activities due to the period of social distancing required by COVID-19, which may have influenced the results related to this variable in the present study.

When analyzing the income variable, there was an absence of significant differences in QoL between families that received higher or lower minimum wages. In contrast, research indicates that a higher socioeconomic level of those responsible is associated with a better QoL of these young people[10]. According to a Belgian study, the social context, shaped by financial status, is a predisposing factor that interferes with the identity of the disease, with an important role in how the adolescent faces and experiences his/her condition[27]. A study conducted in Congo revealed that low socioeconomic status, including low family income, contributes to negative consequences regarding the progression of the disease, especially when dealing with a chronic disease that requires more specialized care, technologies and longitudinal assistance, and these aspects may be difficult to access for more socially vulnerable families[28]. In addition, patients with DM1 require adequate nutritional monitoring to obtain a healthy and balanced diet and, in this sense, nutritional education is a crucial element in the positive outcome of the treatment, and, often, low economic status directly interferes with the types and quality of food consumed by the family[3].

The level of education of the parents of the young people in this sample was not shown to be relevant in relation to the QoL of the latter. However, a US study found that the higher the level of education of the guardians, the better the QoL of adolescents with DM1[29]. Low levels of education directly affect understanding and knowledge about the disease and can compromise the quality of care, with the risk of making it less efficient and prone to errors, and with repercussions, for example, in worsening glycemic control, which affects the QoL of these adolescents[22]. According to a study carried out in Poland, parents' involvement in the management of DM1 is essential for adherence to treatment and for their children's glycemic control, considering that knowledge about compliance with therapeutic recommendations helps in the way these guardians deal with issues related to this disease[30].

T1D is a disease that affects a greater number of people each year and has a direct impact on the lives of young people

with this condition and their families. Efforts to improve the quality of life of these individuals include daily changes in habits and behaviors to achieve a better QoL. Thus, it is worth noting that the findings of this study expand knowledge about the profile of these young people and the conditions that affect them and, in this sense, support reflections for future research.

As limitations of the research, it is recognized that the period of the COVID-19 pandemic may have influenced the responses, for example in the question about the practice of physical activity, since many stopped doing it during social isolation. The sample size is also a limitation, since it may have led to a bias in omitting variables, since the number limited the performance of other statistical tests. In addition, the form and the HRQoL instrument for data collection were extensive and, at the end of data collection, participants may have been tired and compromised their responses. Furthermore, there was a need to group the categories of the outcome variable and profile variables, which may have led to a loss of sensitivity.

CONCLUSION

The adolescents in our study were 52.5% female and 56.3% were between 15 and 17 years old, with 51.3% having been diagnosed with T1DM for 10 years or more. Most of them self-administered insulin with a disposable pen, did not engage in physical activity, did not count carbohydrates, and did not participate in diabetes education groups. The mean values of glycated hemoglobin and bolus insulin units administered in one day were 10.1% and 33.2 IU, respectively. Among the variables described, it was identified that the time since diagnosis is potentially capable of interfering in the quality of life of these adolescents.

The findings in this study allow us to conclude that young people with diabetes have a high quality of life in all domains of the QoLIYPK and classified their health status as good. However, in the concern domain, those with a longer time since diagnosis had a worse quality of life, demonstrating that the concern about the possibility of diabetes interfering with their routine and future life plans impairs the quality of life of these adolescents. Regarding the associations between the variables gender, glycated hemoglobin level, time since diagnosis, and physical activity with Total QoL, no statistically significant associations were found. The Total QoL domain was associated with the variables of the caregivers responsible for these young people, and no significant associations were found between Total QoL and the parents' level of education, marital status, and income.

Since, in our study, the variable time since diagnosis was the one that presented a significant association with quality of life, it is relevant to conduct further research to deepen the understanding of these variables and identify other factors that may influence the quality of life of these young people. Identifying the variables that are potentially capable of modifying the quality of life of this population supports the planning of care actions, ultimately aiming to improve the well-being of adolescents with T1D. Understanding the specific nuances of this group allows nursing professionals to adapt their approaches to data collection and intervention, in order to promote more effective and patient-centered strategies. Thus, this study not only expands knowledge about the reality of these adolescents, but also guides nursing practices that are more targeted and sensitive to their individual needs.

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Thanks to funding agencies

This work was carried out with the support of the Coordination for the Improvement of Higher Education Personnel – Brazil (CAPES) – Financing Code 001 and the National Council for Scientific and Technological Development (CNPq), Brazil – Processes No. 309528/2021-6 and No. 200580/2022-1).

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The authors declare that there is no conflict of interest.

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Received: 11.15.2023
Approved: 02.15.2024

Associate editor:
Helena Becker Issi

Editor-in-chief:
João Lucas Campos de Oliveira